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ABSTRACT

Seven 2001 issues of the newsletter of TASH, formerly The Association for Persons with Severe Handicaps, comprise this document. Each issue typically contains news items, a column by the organization's executive director, reports from special interest groups, legislative testimony, conference information, and several major articles relating to equity, quality and social justice for people with disabilities. The February through November/December 2001 issues address: (1) self-determination, which includes the articles On Choice (Steven J. Taylor), Reflections on Risk (Dick Sobsey), Self Determination (Liz Obermayer), and Securing the Future for People with Disabilities (Al Etmanski); (2) families planning together, which includes A Recovering Behaviorist (Jim McFalls), The Path to Community Participation (Dale Borman Fink), Families Planning Together (Michael W. Smull and others), The Evolution of an Unlikely Partnership between Researchers and Culturally Diverse Families: Lessons Learned (Betsy Santelli and others), and Draft Principles for Individual and Family Self-Determination Partnerships; (3) increasing homeownership opportunities for people with disabilities, which includes articles on Unlocking a Universe of Opportunities in Housing (Becca Vaughn), Expanding Our Thinking on Housing Choice (Charlene Dwyer and Jerry Vogt), Sharing Their Story: The Massarelli Family Shows Legislators the Value of Homeownership (Catriona Johnson and others), and Accessible Home Mean Barrier-Free Friendships (Laura Hershey); (4) the agenda and workshops offered at the 2001 TASK conference; (5) transition as a component of the education process, which includes the articles Inclusion Goes to College: A Call to Action (Cate Weir and others), High School Inclusion + Seamless Transition = Desired Outcomes (Caren Sax and others), and Transition Is a Component of the Education Process (Richard L. Rosenberg and Bonnie Bolton); (6) building friendships and community connections, which includes Fully Funding the IDEA? How about Fully Complying with the IDEA? (Reed Martin), For

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Whom the Bell Tolls: Relationships, Love and Marriage for People with Developmental Disabilities (Dave Hingsburger), Attitude, Educational Practices Serve as Barriers to Friendship (Zech Rossetti and Carol Tashie); and (7) issues in early child care and education, which includes Young Childrens Citizenship in the Literate Community: Significant Disability and the Power of Early Childhood Inclusion (Chris Kleiwer and others), Early Childhood Intervention Personnel Preparation: Backward Mapping for Future Planning (Pamela J. Winton), and A Guide to Achieving Successful Inclusive Child Care--The Harry Potter Way (Peggy Florio). (CR)

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TASH Connections

Priscilla Newton, Editor

Volume 27
Numbers 2 - 11/12
Feb - Nov/Dec 2001

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VOLUME 27 • ISSUE NUMBER 2 • FEBRUARY 2001

TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- What is choice really about?
- Balancing safety and risk
- Living a self determined life
- Increasing Consumer Control through The Ticket to Work Act
- Future Planning
- Developing Personal Networks

Building a Self Determined Life:

balancing choice, safety and risk

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

~

Building communities in which no one is segregated and everyone belongs;

~

Forging new alliances that embrace diversity;

~

Advocating for opportunities and rights;

~

Eradicating injustices and inequities;

~

Supporting research and disseminating knowledge and information;

~

Promoting inclusive education;

~

Supporting progressive legislation and litigation; and,

~

Promoting excellence in services.

From the Editor

With few exceptions, change occurs at various stages of most peoples' personal and/or professional lives. If we are fortunate, these rites of passage will be positive, sustaining experiences that help us to achieve growth and fulfillment as we gain new perspectives, develop greater abilities, and establish broader relationships.

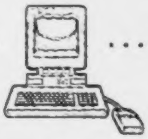
So, too, has TASH's newsletter undergone various transformations over the years. At one time an eight-page publication produced on newsprint, this issue of TASH's news magazine introduces both a new name, TASH Connections, and a new cover design.

What will not change is TASH's continued commitment to provide its members with informative, thought-provoking and inspiring articles, resources and connections.

We appreciate the time many of you have taken to share your opinions about the content of the newsletter, and we invite you to continue to share your perspective about the issues covered in TASH Connections.

Let us know what you think of the new design. Your comments may be sent to my attention at <pnewton@tash.org>.

Priscilla Newton



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- **Don't forget to visit TASH's web site at http://www.tash.org**

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From the Executive Director

BY NANCY WEISS

Over the past ten years there have been important changes in the way people with disabilities and their families choose to obtain supports.

We are moving away from	We are moving toward
Professionals and others routinely making decisions on behalf of people with disabilities	People with disabilities want and need to make their own daily decisions as well as set their own course for the future
People being supported to participate in more inclusive living, learning and work environments only after there has been a professional assessment of readiness	People with disabilities want and need opportunities to participate fully in inclusive home, school and work communities
Focusing on fostering independence through teaching basic educational, daily living, and work skills	Relationship building, and achievement of personal aspirations and quality of life, as it is defined by the person with a disability, are much more important than mastering basic skills

Even though there is clarity amongst people with disabilities, family members, and support providers that these more individualized approaches are better in a multitude of ways, true individualized supports are difficult to achieve. Making the move from more traditional services to more progressive supports presents challenges for organizations, managers, direct support staff, family members, and for people with disabilities themselves.

To say that the changes described above have had positive impact on the lives of people with disabilities is an understatement; indeed, for many it has meant the difference between meaningful lives and segregated existences. There are a number of challenges that are inherent to a conversion to individualized approaches. The failure to address some of these challenges is standing in the way of broader implementation of self-directed supports.

While we are committed to assuring that people have the right to self-directed supports, we need also to identify the skills a person needs to participate fully in the self-determination environment. Young people with disabilities are going to emerge from federally mandated educational programs into support systems that offer opportunities to decide:

- Where and with whom they are going to live,
- What kind of work they will do,
- Who will provide the supports needed for success, and
- What they will do in their spare time toward building relationships, supports, and community involvement.

There is a need for greater focus on what people need to know to make these decisions and how best to teach these skills. Certainly, I am not advocating a return to a continuum-based approach that requires an individual to prove success at one level before being allowed to move to the next. However, there are skills that will be helpful to people with disabilities, family members and professionals alike in navigating the realities of progressive service systems.

We are much more likely to teach skills that we can task-analyze into small teachable steps than we are to teach those skills we have trouble understanding how we ourselves learned. We know all about how to teach someone to sweep a floor; we understand far less about how to teach someone to make and keep friends.

Unfortunately, the latter skill has direct implications for the richness of life, while the former is probably completely irrelevant. A critical analysis of both the supports a person needs to successfully navigate the new opportunities made accessible by the move toward self-determination and the best ways to teach meaningful skills is needed.

Few would argue that the changes toward more self-directed supports have been welcomed, have been too long in coming, and do not yet go far enough. But with these changes have come new challenges for people with disabilities, family members and people providing support. Some of these challenges are openly discussed by self-advocates, family members, and people who work in the disability field, but many are not being openly addressed.

When there was an assumption that professionals knew what was best, individuals with disabilities and their families often relinquished decision-making to the "experts." The selection of a course of action in a given situation, while often counter to the desires of the individual or family, was none-the-less, easily determined. In moving toward a system that is respectful of the individual and his or her family, we have created a support environment in which the best course of action is often unclear.

There is strong agreement that an individual with disabilities has a right to make his or her own decisions, but family members and people providing support confront situations regularly in which the choices an individual makes are discomforting or even potentially dangerous. What is the "right" response when an individual's choices are not benign?

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"Whoever controls the media—the images—controls the culture."
Allen Ginsberg

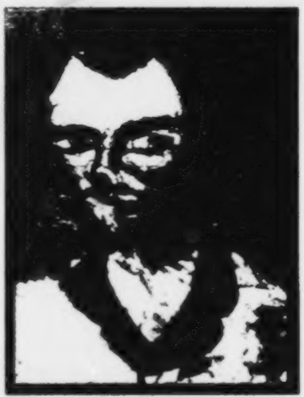
"Imaging the Future"
2001 TASH Conference
Anaheim, California
November 14-17, 2001

BY DENISE MARSHALL, TASH, Director of Meetings and Information Resources

At the meeting last December in Miami, members of the TASH Conference Committee were brainstorming about possible themes for the 2001 meeting. Suddenly the door opened, and 25-30 TASH members joined the meeting with enthusiasm and focus. *"The next conference needs to be about what creates positive images of people with disabilities! The conference will be in Anaheim next year, with the proximity of this location to Disney and Hollywood, now is the time!"* And so, it is.

Daniel Keplinger, about whom the Academy Award winning film *King Gimp*, and the stunning and powerful Cingular advertisement released during the January 2001 Super Bowl were made, has agreed to speak at the opening general session of the 2001 TASH Conference.

> *"I think Cingular showed courage to do something really different and something significant about the importance of self-expression. What I especially liked was the message of the commercial and that I, as an artist, had been cast to symbolize self-expression. Too often the media depicts people with disabilities as a disability, not a person. The Cingular ad, however, is about me as an artist and that's who I am. It's about the intensity and force of my painting and the freedom it gives me to soar. It's about the beauty of self-expression.*



Painting by Dan Keplinger

> *At Parkville High School, an artist was born and the artist was me. Art is what made my identity. In art, I could finally express more of myself. Art came from emotion very deep inside of me, saying what I had never said before, taking me in a new direction as far as I could go and then to a new place. With painting, I could express myself clearly without any body interpreting for me. I am so connected with painting. The headstick is my only hand, although it has no fingers and it's slow, it gets the paint on the canvas. The minute my headstick goes on, I don't hear*

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2001 TASH Annual Conference

"Imaging the Future"

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> *other people in the room, everything is filtered out creating a state of purity possible only through art. I am confined by my physical being, my movement and my speech. When I taste freedom it is intoxication. Art gives me a freedom - a way to communicate."*
>
> ~ Dan Keplinger

Throughout his life, in words and actions, Dan has embodied the values of TASH. We are pleased that he will be joining us in Anaheim, helping to shape an incredibly powerful dialogue about the role of media and advertising in changing the images of people with disabilities.

Energy, enthusiasm, and daring will characterize the TASH conference this fall.
As many of you read last month - the conference was to be held at the Anaheim Hilton, however, that property does not meet the intent of the ADA. TASH stood by our commitment to full access for all and in TASH style, we held out ground and insisted that all means all. When the hotel could not comply, we pulled out of the contract and successfully negotiated with the Hilton to release us without penalty.

TASH is very pleased to announce that the conference will remain in Southern California. It will be held at the Marriott Anaheim and the Anaheim Convention Center. Cal-TASH, the California Chapter of TASH, will be co-sponsoring the conference in lieu of holding a conference of their own. Opportunities to be innovative abound!

We have long understood that greatest obstacles faced by people with disabilities and their families are imposed by society. Advertising and media are just one of the ways images are formed. Understanding the influence that evokes positive images and attitudes toward people with disabilities is critical to effecting social change. Words, stories, movies, pictures, ads, articles, cartoons, books, and everyday interactions in the community are used to prove or disprove the beliefs that shape systems.

This year the conference committee has identified interest in presentations that address this theme of images. Proposals may be submitted on topics that demonstrate stories and strategies that have changed images, attitudes, systems, and empowered people to realize the full inclusion of people with disabilities in their home communities. Be a part of shaping the conference by submitting to do a presentation, or encouraging friends and colleagues to be at this exciting gathering. For questions and guidelines about presenting visit our website at <http://www.tash.org> or call Kelly Nelson at extension 105, 1-800-482-TASH (8274) or 410-828-8274.

For more information about Dan Keplinger, visit his website at <http://users.erols.com/kinggimp/>

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TASH: Public Policy in Action

IDEA Full Funding Act Introduced

Representative Charles Bass (R-N.H.) will be reintroducing a bill to make mandatory the full funding of IDEA 97. The Mandatory IDEA Full Funding Act sets a five year timeline to provide the full authorized level of funding for Part B (assistance to states) set by Congress 25 years ago. What makes this bill different from the previous bills and "resolutions" is that the funding will be mandatory — no longer subject to "such sums as appropriated" by the Congress, but guided by the following percentages of the average current per-pupil expenditure in public elementary and secondary schools:

20% for fiscal year 2002; 25% for fiscal year 2003; 30% for fiscal year 2004; 35% for fiscal year 2005 and, in 2006, state education agencies and local school districts can expect funding levels to reach the authorized 40% and remain at that level for each subsequent fiscal year.

A large number of education organizations including the American Association of School Administrators (AASA) and the National Education Association (NEA) have supported this language in the past and are expected to enthusiastically endorse this bill when it is reintroduced in the next few weeks. The AASA has made mandatory funding of IDEA an organizational priority and will make a "major push all through September 2001" to get the proposal passed.

* * *

Supreme court issues decision in *Garrett*

The Supreme Court handed down its decision in the Board of Trustees of the University of Alabama v. Garrett et al case on February 21, 2001. In a 5-4 decision, the Supreme Court held that "Suits in federal court by state employees to recover money damages by reason of the State's failure to comply with Title I of the ADA are barred by the Eleventh Amendment" (which grants states "sovereignty" making them "immune" from certain types of judicial actions). Simply put, this means that people with disabilities cannot sue their states for money under Title I of the ADA.

In a forceful dissent, Justice Breyer, joined by Justices Stevens, Souter and Ginsburg argued that the Court was taking away the authority of Congress to "sponsor and support" the 14th Amendment guaranteeing "equal protections under the law." Further, Justice Breyer took issue with the statements of the majority of the Court that "the legislative record of the ADA . . . simply fails to show that Congress did in fact identify a pattern of irrational state discrimination in employment against the disabled." In doing so, he appended the dissent with over 35 pages of State-by-State examples of discriminatory actions presented in response to 13 Congressional hearings and field hearings held in every state by the Task Force on the Rights and Empowerment of Americans with Disabilities, attended by more the 30,000 people.

If there is a positive "side" to the Garrett decision, it is that Justice Rehnquist wrote a very narrow opinion, applying only to money damages and to Title I of the ADA concerned with employment. Individuals with disabilities can file discriminations suits and request "injunctive relief." This means that successful lawsuits can require that employers fix the problems, restore employees to their former positions, and provide the accommodations necessary for successful employment. In addition, people can still recover attorneys' fees if they prevail.

So, what are we to think? First, the ADA is **NOT** dead. This was a limited decision, primarily about money and pertaining specifically to Title I of the ADA. Nonetheless, important remedies were taken away from individuals seeking to secure their civil rights. Outrageous, too, is the idea that what the Congress sees and hears is somehow not "enough," and that the idea opined in the majority opinion that there is not "evidence" of systematic discrimination in employment is refuted by the appalling unemployment rates of people with disabilities.

In his January 3 "New Freedom Initiative" proposal President George W. Bush stated *"Because of the ADA, discrimination against a person with a disability is not just unkind or cruel or wrong: it is an infringement of federal law, and a violation of civil rights. But the banning of discrimination is just the beginning of full participation in our society. Though progress has been made in the last decade, too many barriers remain. Too many Americans with disabilities remain trapped in bureaucracies of dependence and are denied the tools and access necessary for success. My Administration is committed to tearing down these barriers."* Today the Supreme Court has erected a new barrier for the President to overcome WITH us as we seek the full participation that he has pledged to support.

* * *

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GOVERNMENTAL AFFAIRS UPDATE

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The Family Opportunity Act of 2001

The Family Opportunity Act of 2001 was reintroduced on February 8, 2001. Sponsored by Senators Kennedy and Grassley and Congressmen Waxman and Sessions. The goal of the Family Opportunity Act is to give more children with disabilities access to a broad range of health care services and supports. The vehicle to achieving this is to give parents the option of buying into Medicaid and paying on a sliding scale basis. This Medicaid buy-in is important because it is designed to offer a very broad range of services. The bill will allow states to offer Medicaid benefits to middle-income families of children with disabilities for the first time (middle income is defined as 300% of poverty, which is $51,150 for a family of four in most places). The Family Opportunity Act does not mandate that states provide this option; it allows them to offer the "buy-in." Medicaid is a state-administered program, with the federal government providing "matching" funds and oversight.

To sign up for the Government Relations listserve or for information about specific policy issues or legislation, contact Jamie Ruppmann, Director of Governmental Relations, at (410) 828-8274, ext. 104 (voice); (410) 828-1306 (TDD); or (410) 828-6706 (fax).

From the Executive Director

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Take, for example, a support person who privately wonders whether it is wise to allow an individual with frequent grand mal seizures to travel back and forth from work unaccompanied; what should the role of family members and support staff be when a person chooses to continue to smoke in the face of life threatening emphysema; to have unprotected sex with an individual known to have AIDS; to make him/herself vulnerable by walking through dangerous parts of the city late at night; or to ride a bicycle with no regard for safety? When, if ever, is it appropriate to intervene or to even propose a plan that is counter to an individual's choices? How imminent must the risk be?

Some people feel that it would not be right to intervene in situations such as those described above under any circumstances, citing the fact that people without disabilities have the right to make choices, and often do make choices, that are unwise. Others would feel it their responsibility to assure safety and well-being. What is absolutely true is that the best decisions will be made when people are able to engage in an open discussion that takes into account the varied points of view of all stakeholders.

Robert Perske discussed the importance of risk taking as far back as 1972[1]. In the ensuing years, the importance of allowing, even purposefully incorporating, opportunities for risk-taking has become well-accepted practice, but people also value safety and success. When the values for safety and risk conflict, decision making becomes complex. Sometimes each stakeholder in a situation is clear about his/her own values but those beliefs conflict with those held by others.

A young woman's parents, for example, may support their daughter's decision to leave her group home for an apartment of her own, while staff may have genuine concerns that she will not be successful. Just as often, values conflicts occur within, rather than among, individual stakeholders. That is, any or all of the individuals participating in this discussion of living environments (including the young woman herself) may at once value the move toward independence while fearing the consequences of this important step.

Even in the most progressive agencies one can observe person-centered planning meetings at which all participants are nodding their agreement to a proposed plan while privately, many may worry that they are alone in the concerns they harbor. Reluctant to be viewed as less than progressive or politically incorrect, such doubts are not voiced. Support staff are likely to be influenced by the anticipated responses of others, including co-workers, supervisors, neighbors, or funding agencies. Family members may have difficulty viewing their son or daughter as a person who is maturing and changing or, conversely, may know a much more competent side of the individual than staff are able to perceive. The individual him or herself may be cognizant of both the risks and benefits of a given course of action.

It must be the goal of progressive organizations to develop cultures that promote open discussion and a sense of safety for all team members to express themselves candidly. When values conflict, the challenge to both individuals and organizations is to weigh the strength of one person's belief against those held by all stakeholders. Open discussion about beliefs and concerns is critical. Environments in which every participant feels safe to voice concerns, including those concerns that may seem out-of-sync with progressive approaches, allow each stakeholder to balance his or her own point of view with the viewpoint of the individual and the positions of other stakeholders.

Without losing sight of the fact that an individual's choices are to be respected, organizations must find ways to encourage decision-making processes that value and encourage an open exchange of ideas. By focusing on the skills needed to determine one's own future and by encouraging open discourse on values conflicts that arise, we will have accomplished much toward assuring quality individualized supports for greater numbers of people with disabilities.

Reference:

[1] Perske, R. (1972). The dignity of risk and the mentally retarded. Mental Retardation, 10 (1), 24-26.

On Choice

BY STEVEN J. TAYLOR

The concept of "choice" is discussed frequently in the field of developmental disabilities these days. Yet the concept means different things to different people, and is used to justify radically different visions of the place of people with developmental disabilities in society. This article presents some thoughts on the concept of choice.

Why is choice important?

Historically, people with disabilities and their families were offered few, if any, choices in their lives. Families of children labeled with severe disabilities had two options: to place their children in institutions or keep them at home with no publicly funded assistance or education. Adults labeled with severe disabilities could be placed in public institutions or live in the community with no services or supports.

With the establishment of a federally guaranteed right to education and the expansion of community services, the options available to people with disabilities and their families slowly started to expand. Nevertheless, many people continue to be denied the opportunity to make choices about the most basic aspects of their lives.

What is choice really about?

In my view, choice means that people with disabilities, regardless of the severity of the disability, should be able to enjoy the same choices and options available to other people in society. A public commitment to choice means that public funds and programs should support people in making these choices and selecting these options. It does not mean that public funds and programs should support lifestyle choices and living conditions other people do not enjoy.

What are some important choices that people should be able to make?

All people should be able to make decisions over various aspects of their lives. For adults, major choices include decisions about:

- In which communities and neighborhoods to live

- Whether to live alone or with others and, in the case of the latter, the specific person or persons with whom to live

- Friendships and participation in community activities and associations

- From whom and how to receive personal assistance and support

- Sexuality and sexual relations

- Where to work

- Medical treatment and therapeutic interventions

Choices about these matters determine the degree to which people can make decisions about day-to-day things such as:

- Meals and mealtime routines
- Bedtime routines
- How to spend leisure time
- Dress and personal appearance

What public policies and approaches are consistent with choice?

Public policies and service approaches should maximize personal control and choice. The following are some current approaches consistent with this principle:

⊙ Individualized funding. Sometimes referred to as "self-determination" or "cash and counseling," individualized funding provides individuals with funds to arrange for their services and supports. A fiscal intermediary and service coordinator may be used to assist people in managing funds allocated to them.

⊙ Person-directed personal assistance. Under this approach, people are able to select, hire, supervise, and, if necessary, fire their support staff or personal assistants.

⊙ Person-centered planning. This is a planning approach designed to identify people's capacities, needs, and desires.

⊙ Home of Your Own. This involves innovative financing schemes to enable people with disabilities to own their own homes as opposed to living in agency operated facilities.

⊙ Family-centered support services. For children, in particular, families should control the services offered to them.

People without disabilities can make poor choices. Some people pursue unhealthy lifestyles or spend their money unwisely. Disability is not a reason for depriving any person from making the same choices other people have the right to make.

Are all people capable of making choices?

All people should be presumed competent to make choices about their lives. Some people, however, may be limited in their ability to express their decisions. In these instances, every effort must be made to ascertain their preferences and choices by people who know them well. Surrogates — parents, family members, and guardians — will sometimes need to

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On Choice

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make decisions on peoples' behalf when it is impossible to determine what they want. The choices that surrogates make in such circumstances should be limited to the range of choices and opportunities available to people without disabilities.

What about people who make bad choices?

People with or without disabilities can make bad choices. Some people pursue unhealthy lifestyles or spend their money poorly. Disability is not a reason for depriving any person from making the same choices other people have the right to make. Nor is disability a reason for supporting people with disabilities to make decisions (e.g., physician-assisted suicide) that persons without disabilities are not entitled to make.

Family members, friends, and loved ones can and do influence the behavior of others. The strongest safeguard of the well-being of any person is to be involved in caring relationships in which people influence each other in non-coercive and non-manipulative ways.

Choice should never be used to justify neglect, poverty, or an absence of realistic options. People do not choose to go hungry or be homeless. To people who might make bad lifestyle or spending decisions, we should be magnanimous.

> Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities.

How has the concept of choice been misused?

Increasingly, choice is used by some individuals and groups as a justification for the continued institutionalization of some people with developmental disabilities. What is usually meant by this is that parents and family members should have the option of deciding where and how their sons and daughters with disabilities should live. Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities. The condemnation of institutions by organized self-advocacy groups testifies to the fact that people with developmental disabilities do not wish to be put away.

The phrase "one size fits all" is sometimes quoted by proponents of institutions to characterize the policy of community inclusion. Yet, it is the institution — with well-documented patterns of "block treatment" and rigidity of routines — that epitomizes "one size fits all." In the community, there is unlimited variety and opportunity to pursue lifestyles based on individual needs and preferences.

Any adult has the right to decide with whom to associate. Some groups have chosen to segregate themselves from the wider society based on religious, ethnic, and other grounds. Some parents choose to send their nondisabled children to boarding schools where they can be with students of similar ethnic, religious, or economic backgrounds. In a democratic society people have the right to choose segregation — to associate with only those persons presumed to be exactly like themselves. But society has no responsibility to subsidize segregation. Public policy toward people with disabilities should support opportunities to make the same choices other people make — nothing more and nothing less.

THE FOLLOWING BULLETINS AND FACT SHEETS RELATED TO CHOICE ARE AVAILABLE FROM THE CENTER ON HUMAN POLICY:

Policy Bulletin on Safeguards (1993) addresses how safety can be increased by strengthening community and improving the assistance people receive. It also discusses the paradox of regulations. (18 pages)

Fact Sheet on Self-Advocacy (1999) by Mair Hall briefly defines what self-advocacy is, provides a brief history of the Self-Advocacy/People First Movement, and includes a brief list of resources. (2 pages)

Fact Sheet: Summary of Self-Determination (1998) by Michael J. Kennedy and Lori Lewin summarizes what self-determination is and is not, the principles of self-determination, the values supported by self-determination, and a call for changes in the system in order for self-determination to truly succeed. (2 pages)

Fact Sheet: In Support of Families and Their Children (2000) by Nancy Rosenau discusses why children belong in families and how to assure families for all children. (2 pages)

Feature Issue on Institution Closure (Winter 1995/96) edited by Mary F. Hayden, K. Charlie Lakin, and Steve Taylor contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

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Center on Human Policy.
Fact Sheet: What is "Permanency"? (2000) by Nancy Rosenau describes the importance of permanency for children and discusses strategies to support and implement it. (2 pages)

Fact Sheet: The Community Imperative (2000) In 1979, the Center on Human Policy at Syracuse University wrote The Community Imperative, a declaration supporting the right of all people with disabilities to community living. The Center has reissued The Community Imperative in 2000 and invites endorsements from individuals and organizations.

Internet Resources Related to Choice

Advocating Change Together
http://www.selfadvocacy.com/

Self Advocates Becoming Empowered
http://www.sabeusa.org/

National Program Office on Self-Determination
http://www.self-determination.org/

Center on Human Policy
http://www.soeweb.syr.edu/thechp/

National Home of Your Own Alliance
http://alliance.unh.edu/

Institute on Community Integration, University of Minnesota
http://ici.umn.edu/

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REFLECTIONS ON RISK

BY DICK SOBSEY

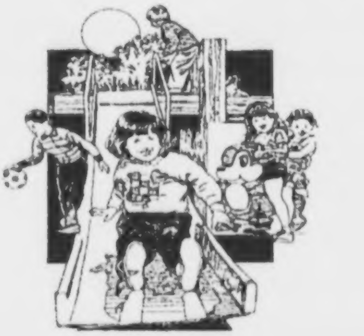
For about thirty years now, I've been thinking about the risks and how to manage them. I remember one of the things that made me start thinking about different kinds of risk a long time ago. It was an article by Bob Perske (1972) about the dignity of legitimate risk. I'm not sure now if that was the first time I read something by Perske that made me think and rethink things, but it was certainly not the last. His work over the years has had wonderful impact on a lot of us, making us look at things from a slightly different perspective, making us think a little differently and, more importantly, making us feel differently about things.

I had been working in a large institution for a long time then. One of the main reasons that people ended up there was that someone wanted to protect them from the outside world. I have no doubt that there really were some risks that they were spared by being "put away," but there were a lot of other risks that increased. Hepatitis, a wide variety of parasites and other communicable diseases were common. In the crowded and understaffed dining halls, people choked to death because they learned to stuff food in their mouths as quickly as they could before it was stolen by another resident or taken away by staff. Everyone was neglected. Most were assaulted, and many were sexually abused.

I thought of one young man who had recently died there. Another resident of the institution had gotten a small jar of peanut butter. It was his most precious possession, and he kept it in his shirt so it would not be stolen. One day, the glass jar slipped out and smashed on the floor. As the former owner of the peanut butter stood in shock, Mark, as I'll call him here, deftly scooped up the mixture of broken glass and peanut butter, and he ate it. Of course, eating broken glass is never a good idea but broken glass mixed with peanut butter is a lot worse. Mark seemed to be recovering, but suddenly died a couple of weeks later. I felt sad about it, but reading that article, tears of grief turned to tears of rage. I wanted a gravestone for Mark that said, "Dead at 24. Protected from the risks of a normal life."

Since then, I think a lot about risk. In the middle of writing the paragraph above, my son's school called to say, "David got hit in the face by a soccer ball, and he's bleeding from his nose and mouth." By the time my wife, Louise, and I got to the school, David seemed fine, and most of the blood had been cleaned up. David's disability makes it hard for him to protect himself when playing with other kids. Nevertheless, David is in the game. The boy who kicked the ball is a friend of David's. He comes over to play at our house from time to time. So are most of the other kids who were playing soccer that day.

David has had no more and probably a lot fewer cuts, scrapes, bruises, bloody noses than most ten-year-olds I know. So the risk of playing with other kids is a normal risk. Furthermore, it is a risk that David chooses to take. As parents there may be times when we have to step in because the risk is too high. When the risks are reasonable, however, why not let David make his own decision?



Louise and I would like to keep him perfectly safe, but the risks associated with being in the game are actually a lot less than the costs of keeping him out of it. He can get hurt playing with other kids, but that risk does not justify the cost of giving up his chance to have friends. About 150 years ago, one authority on risk management summed it up as follows: "*'Tis better to have loved and lost than never to have loved at all.*" (Tennyson, 1850).

A lot of the risk that people seem concerned about these days is the risk for abuse and exploitation. I've been one of the agitators that have been worrying people about this. I've spent a lot of the last 15 years trying to get people to see that violence is a huge problem for people with disabilities, so I am not going to trivialize it now. Nevertheless, I do need to say that misguided attempts to protect people can do more harm than good. I suggest two tests to determine whether protection strategies are appropriate. First, identify to what degree the risk is controllable and how much difference the prevention strategy is likely to make. Second, consider the cost to the individual who is being protected, particularly social and emotional costs.

For parents and family members who are horrified to learn that children with disabilities are more than three times as likely to be abused as other children, it is important to think about two kinds of potential abuse -- intrafamilial and extrafamilial. Intrafamilial risk is the most controllable. Many children with disabilities are abused by members of their own families, most often parents.

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The "good" side of this sad fact is that we actually have a lot more control over this. If, as a parent or family member, we can honestly feel secure that our child and loved ones are safe with us and reasonably secure that he or she is safe with the rest of our family, we immediately remove a large slice of that increased risk.

> **Restricting people from doing what they want in order to keep them safe is disempowering. This does not mean that restricting an individual's choices is always the wrong thing to do, but in my opinion many use it much too often. It should be used only when the stakes are high, harm is likely, and there is no empowering or even less intrusive strategy available.**

If some of us are not 100% sure that our child or loved one is safe with us, the most important thing we can do is to get the help we need. If anyone is suffering from depression, has anger management problems, or is having difficulty coping with stress, he or she needs to deal with those issues.

There are also reasonable strategies for minimizing risk for abuse from external sources. Choose caregivers and programs carefully. Use agencies that check police records and screen staff carefully. Ask agencies about their policies. Avoid agencies and programs that isolate you from your child.

For example, if a day care has no unobstructed windows, makes you ring a buzzer to get in, then keeps you in the office while your child is brought to you, it is probably time to get your child out of there. Parents and families should have a way to see what things are like when visitors are unexpected. Of course, this does not mean that there is no security to keep strangers from entering, but security is not an excuse for isolation.

In considering the cost of violence prevention strategies, think about whether strategies empower or disempower the people who they are supposed to protect. Better communication and sex education, facilitating appropriate social and sexual relationships, and empowering people to chose and reject where they go and who they go with are all strategies that can keep people safer.

Restricting people from doing what they want in order to keep them safe is disempowering. This does not mean that restricting an individual's choices is always the wrong thing to do, but in my opinion many use it much too often. It should be used only when the stakes are high, harm is likely, and there is no empowering or even less intrusive strategy available.

For example, we would not allow our son to go out to the store by himself because there is good reason to believe he would be in serious danger. For now, that restriction is justified. If he can learn to keep himself safe, however, that would replace a restrictive strategy for protection with an empowering one. Risk can also be categorized by its political impact. There has been a lot of discussion of the relative risks of institutional placement and community alternatives. Some researchers have suggested that deinstitutionalization has been accompanied by neglect, abuse, and increased death rates. Others have argued that this analysis is biased and that the risks are actually much higher in institutions. Service providers and parents also have politicized risks at times. A social worker once told me about a group home they found where former residents of a large institution were kept in chains and abused. While they got the residents out, they did not report the abuse because they felt that the publicity would slow down the move to the community, which they believed was more important. The father of a young man who lived in an institution once told me that his son had been abused there, but he would not report it because he strongly believed that the institution was the best place for his son. In his words, he "did not want to drive another nail in the coffin" of the institution. In my opinion, both of these individuals are making a serious mistake. The moment we agree not to confront the problems of abuse and neglect because confronting the problem conflicts with some greater goal, we have accepted abuse as a permanent reality.

Risk in these arguments becomes a political pawn for a much broader agenda. As a researcher, I will tell you that I still believe that the risk of violence and neglect is higher in isolated institutions. I also need to say: (a) the comparisons are difficult to make in a completely objective way; (b) there are good arguments made on both sides; and (c) deinstitutionalization, in itself, has not and will not solve the abuse and neglect problem. The more important concern, in my view, is that politicizing the issue of risk for or against community living is wrong. Both sides need to pay more attention to solving the problem and less attention to whose agenda is served.

The living conditions in some group homes and other community-based living alternatives have been horrible (e.g., Horwitz & Boo, 2000). No one should have to live under those conditions. The concerns raised about death rates and other problems (e.g., Strauss & Kastner, 1996) among people returning to the community should not be simply ignored or repudiated by advocates for community living. People have a right to life in the community AND they have a right to decent living conditions. No one should have to choose one or the other, and realizing the promise of community living does not mean just being a little better than an institution.

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A hundred years ago W.E.B. DuBois (1901-1969) wrote eloquently about the hardships faced by former slaves returning to the community. The problems that he identified were significant ones, and some people tried to use DuBois' work to argue that abolition had been a mistake. DuBois did not let himself be drawn into the argument of whether emancipation might have done more harm than good. He did not ignore the problems to avoid the argument.

Instead, DuBois insisted that all people had a right to their freedom and a had right to decent living conditions. In much the same way, we need to face the risks of abuse and neglect in community settings squarely. We need to continue to push for community living, but we also need to push just as hard for quality services that keep people safe.

Dick Sobsey is Director of the Developmental Disabilities Centre at the University of Alberta, Edmonton, and a member of the TASH Executive Board of Directors. Questions or comments concerning this article may be directed to Mr. Sobsey by e-mail at <dick.sobsey@ualberta.ca>

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Self Determination

BY LIZ OBERMAYER

I am a person with a developmental disability and like most people with a developmental disability, I usually was told what, when or how to do something. Sometimes I wasn't even given a choice. This went on for years and years. Parents and professionals didn't think anything of it, and people with developmental disabilities didn't know any better, because that's how life was. Other people made all kinds of choices for us, ranging from where to live to as simple a matter as what to wear.

That is until my friends and I learned about something that people have been calling self determination. Self determination is a very simple concept. I think. People with disabilities are just saying that we should be able to control our lives just like anyone else does. That means simple decisions like what to wear or eat or where to live, to more complicated tasks like controlling our own resources.

Parents and professionals usually will say that we shouldn't be able to control or make decisions for our lives because we can't make responsible and good choices. My argument to this is that all people can learn from events or decisions that may not turn out as planned. Another argument could be that I am sure not every decision or choice my parents or someone made would turn out to be a good or a responsible choice.

Self determination has changed my life for the better because for the first time, I am learning about what it means to control my life. As I have understood the concept, there are four main points to self determination. They are freedom, authority, support and responsibility. I will now describe how each concept effects my life and the live of my friends:

Freedom: In my opinion, this is the most important principle because for such a long time people with disabilities were not allowed to live a free life even though our country is based on this fundamental right. Most of the time people lived in an institution or a controlled environment. For the past couple of years, I have lived in a world where I make the decisions and I can make choices for myself.

I also have the freedom to come and go wherever I want, and make the decision whether I want to tell someone where I am going. I refuse to go back to a world where I am controlled. My friends also enjoy the same kind of freedom I enjoy.

Authority: When I looked up the word " authority" in the dictionary, it says something like the power to influence a command or thought. To me it means, I have the authority or power over my life and I have the final say over things. My friends and I struggle everyday to get the authority over our lives because I think some people without disabilities don't see us having the capability of having the authority over our own lives.

For example, when I was moving from Massachusetts to the Maryland area, my parents helped me get my apartment. We saw two apartments and then when it came down to making the final decision, I made it all by myself, based on what I wanted. This wasn't the case when I moved to Boston from a controlled environment.

Support: This is my favorite principle of all because I think everyone, regardless if you have a disability or not, needs some kind of support. When I no longer required paid support, I formed a circle of support. I like calling it a circle of friends. The reason why I call it that is because I would like to get my support from my friends, not from people who just support me because they have to. I think if people don't get support then people, regardless of disability or not, won't have happy and productive lives.

My circle is a circle that I give support to just as much as they support me. I worry sometimes that people with disabilities take advantage of people who support them. I mean sometimes people with disabilities will expect people without disabilities to help and they don't offer anything in return. This is fine if the person is getting paid to help you, like used to be the case with me, however now it's not. Sometimes all I can do is to listen to my friends' problems, but there are other times I can do more. I like knowing that I am making my friends feel better because it makes me feel like it's a true friendship. My friend, Nancy Ward, once said that support should "go both ways."

Responsibility: This principle is also one of the important principles of the self determination movement. I also enjoy talking about this one. A lot of people without disabilities will often complain that people with disabilities don't want to take responsibility for their own life. They say that people with disabilities would like all the rights and privileges that go along with living and working in the community, however when it comes to taking responsibility to live or work in the community, that's another story.

Just as there may be a certain percentage of people without disabilities who do not want to work, you will find a segment of people with disabilities who feel the same. However, there are a lot of people with disabilities who do want to contribute to their communities and earn their own living using their own skills and talents. Lots of people with disabilities work at their chosen profession everyday, just as lots of people without disabilities do. And those of us who choose to work and are given the opportunity to work, understand that it is our responsibility to do so if we can.

Last year, we as self-advocates added a fifth principle, Self-Advocacy. We believe that if it wasn't for self

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THE TICKET TO WORK: A TOOL INTENDED TO INCREASE CONSUMER CONTROL OVER EMPLOYMENT SUPPORTS

BY JOHN BUTTERWORTH, DAVID HOFF, ELENA VARNEY, AND JOE MARRONE

NOTE: The information in this article is based on proposed regulations that were published in December, 2000. The final regulations may change some of the details of the Ticket to Work program.

In December 1999, President Clinton signed into law the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA), to enhance the ability of people with disabilities to go to work. This new law does a number of things, including requiring SSA to establish a "Ticket to Work and Self-Sufficiency Program," where individuals receiving Social Security disability benefits (SSI or SSDI) can choose services to assist them in finding and maintaining employment, and reduce their dependence on cash benefit programs.

The Ticket to Work program will be implemented beginning in 2001 on a state-by-state basis. Despite significant concerns about the regulations that have been proposed, the Ticket offers the potential for individuals to have greater control over their employment supports. This article provides an overview of the Ticket program based on the proposed regulations. The TASH Employment Committee encourages individuals and organizations to use the Ticket as a tool for individual and organizational change, and as leverage in redirecting resources to integrated employment.

This summary is based on regulations for the Ticket program that were proposed in December, 2000. The Social Security Administration is expected to publish final regulations in the Spring of 2001. In the preamble to the regulations for the Ticket to Work, SSA makes it clear that the program has two compatible goals:

- "To expand the universe of service providers available to beneficiaries with disabilities who are seeking employment services, ..."
- "...To provide beneficiaries with real choices in getting the services they need to obtain, regain, or maintain employment."

The Ticket to Work Program - What Is It?

The basic idea of the ticket program is to maximize choice by allowing you to select your own employment or rehabilitation provider, and for Social Security to pay that provider based only on a successful outcome. This outcome is defined in the law as successfully getting a person in a job which provides sufficient income that you no longer get a monthly SSI or SSDI check.

The ticket program is being phased in nationally over a three-year period beginning in 2001. The first tickets will be issued in 2001 in the following states: Arizona, New York, Colorado, Oklahoma, Delaware, Oregon, Florida, South Carolina, Illinois, Vermont, Iowa, Wisconsin, Massachusetts. By January 1, 2004, the ticket program will be nationwide.

When the ticket program begins in a state, individuals receiving Social Security disability benefits (SSI - Supplementary Security Income; SSDI - Social Security Disability Insurance) will receive a "ticket" (a paper document). The person with a disability can then use this "ticket" to obtain services to help them find and keep a job. The organizations providing services under the ticket program are called Employment Networks (EN).

What types of organizations can be Employment Networks?

A wide range of organizations can be Employment Networks. These include both public and private organizations. State Public Vocational Rehabilitation agencies must be an Employment Network, if they wish to receive any funding from SSA for providing services. Other Employment Networks can include: other state, county and local public agencies (including Mental Health, Developmental Disability/Mental Retardation agencies), community rehabilitation providers, supported employment agencies, schools, One-Stop Centers, and similar organizations which have traditionally been in the business of helping people find employment. (SSA also expects that some non-traditional entities may wish to become Employment Networks.)

What is my ticket worth?

The amount paid to an Employment Network is based on a percent of the prior calendar year's national average disability benefits payable under Title II (SSDI) or Title XVI (SSI), and not on the individual's benefit amount. The amounts will be adjusted on an annual basis for cost of living. The charts at the bottom of this page outline the two payment systems as proposed.

Employment Networks receive monthly payments only for those months when the beneficiary does not receive a check from SSA. Therefore, while an EN can receive up to 60 monthly payments, these months may not be consecutive. In fact, under the proposed regulations, these 60 monthly payments could be spread out over up to 14 years from the time an individual first starts receiving services under the ticket program.

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THE TICKET TO WORK: A TOOL INTENDED TO INCREASE CONSUMER CONTROL OVER EMPLOYMENT SUPPORTS

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However, if an Employment Network is able to quickly assist you in finding employment, and you work steadily at a job with sufficient income so that you don't receive a social security check, the Employment Network could receive all 60 payments in about 5 years.

The proposed regulations outline two payment systems that an Employment Network must choose from:

❖**Outcome payment system**: The Employment Network receives a flat monthly fee for each month (up to 60 months) that the individual does not receive a check from Social Security. (Note: The regulations specify that the individual receive no federal benefit, implying that in states where the state supplements the federal check, the individual could still be receiving that supplement in the form of a check from SSA).

❖ **Milestone payment system**: The Employment Network receives two "milestone" payments along with a reduced monthly outcome payment for up to 60 months. Both milestones occur after the individual is working at aboveor above substantial gainful activity (SGA), currently $740/month, but may occur before the individual stops receiving a check from Social Security. The total payments to the EN will be lower than under the outcome payment system (section 411.535).

How much do I have to earn to eliminate my monthly social security check?

SSDI

Currently, SSDI checks for individuals stop when you earn more than $740 per month ($1170 per month for individuals who are blind), and you have used up all your trial work months (trial work months are months when an SSDI recipient earns over $530 per month; SSDI recipients can work for 9 trial work months over a rolling five year period without impacting their benefits, and receive checks for 3 more months when the trial work months have been used up).

SSI

Unlike SSDI, there is no standard income level where your SSI check is reduced to zero. Instead, the amount varies, depending on the amount of your monthly SSI check from the federal government. The formula to calculate this is: [(Monthly SSI Payment - State Supplement) X 2] + $85. (Many states add an additional amount to SSI checks, which is called the "state supplement"; under the ticket regulations, only your federal SSI payment has to be reduced to zero for the EN to be paid.) The current average monthly federal SSI cash benefit is $440, so for evaluating the ticket program, it is reasonable to use a figure of $965 as an approximate average amount of monthly income where an SSI check would be reduced to zero. However, the required income could be higher, since the maximum SSI benefit for an individual is $530, requiring an income of $1150.

How else will the ticket program help individuals?

Suspension of Continuing Disabilities Reviews while Using the Ticket. SSA conducts continuing disability reviews (CDRs) to determine whether or not you continue to be considered disabled according to SSA's definition and criteria. Social Security benefits end if medical or other evidence shows that you are no longer disabled. SSA must conduct CDRs at least once every 3 years for most recipients. Persons deemed permanently disabled are reviewed less frequently, usually every 5 to 7 years. While participation in the ticket program is voluntary, a major incentive for people with disabilities to use the ticket is that you cannot have a CDR while your ticket is assigned to an Employment Network, (Subpart C).

The Ticket and Individual Choice and Control

The regulations contain a number of elements so that people with disabilities have choice and control. These include:

- Participation in the ticket program is voluntary.

- If you are dissatisfied with your Employment Network you may assign your ticket to any Employment Network or State Vocational Rehabilitation (VR) agency that is willing to provide services. (Employment Networks have a similar right to decide to no longer provide you services, and no longer accept your ticket.)

Employment Network payments under the outcome system

	Months 1-60	Total payments
SSI	$176/month	$10,560
SSDI	$277/month	$16,620

Employment Network payments under the Milestone system

	Milestone 1	Milestone 2	Months 1-12	Months 13-24	Months 25-36	Months 37-48	Months 49-60	Total Payments
SSI	$300	$600	$57/mo.	$141/mo.	$150/mo.	$158/mo.	$167/mo.	$8,976
SSDI	$470	$940	$90/mo.	$222/mo.	$235/mo.	$249/mo.	$263/mo.	$14,127

Note: Individuals receiving both SSI and SSDI fall under the payment schedule for SSDI recipients.

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THE TICKET TO WORK: A TOOL INTENDED TO INCREASE CONSUMER CONTROL OVER EMPLOYMENT SUPPORTS

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● Employment Networks do not get paid, unless they find you a job that pays you a sufficient income so that you no longer receive a social security check.

● An individual work plan (IWP) (or, in the case of a State VR agency, an individualized plan for employment [IPE]) which is agreeable to you, must be developed before you assign your ticket to an Employment Network.

● You and the Employment Network share the responsibility for determining the content of the individual work plan. IWP.

● When you go and talk to an Employment Network about possibly using their services, the EN must provide you with a copy of its most recent annual report, which lists specific information on the results achieved with individuals in the ticket program, to help you decide if the EN is the right one for you.

What are the concerns about the Ticket program?

⊙ The biggest concern is that the ticket program does not by itself provide enough resources to cover the job search and job support needs for an individual with significant support needs. This means that the ticket may be most useful combined with another funding source such as funding from an MR/DD or MH agency. Combining the ticket with the funding from a VR agency is more complicated, since the VR agency functions like an employment network and can take the ticket itself.

⊙ Reassigning the Ticket (and thereby having full control over the source of support services) may be more difficult if you are combining the Ticket with other funding sources to find work.

⊙ For the ticket to have value to an employment network, individuals do need to be earning a significant wage. Many individuals in supported employment do not reach the wage levels required under the ticket. This is both good news and bad news. The ticket, if it is successful as a program, may provide incentive to service providers to seek better jobs with higher wages and work hours. The bad news is the individual needs to clearly have the goal of reaching that level of work.

⊙ The requirements for work under the ticket program appear to recognize that it may take time for some individuals to work towards self-sufficiency, possibly with cycles of relapse and remission. While this may sound reasonable from the ticket users perspective, if an individual is able to comply with only the minimum requirements, it may be difficult for the Employment Network to justify the cost of services:

- under the outcome system, the Employment Network will receive no payment until year five (unless an individual on SSDI has previously used up his/her trial work months)
- under the milestone system, the Employment Network would receive only two payments prior to year five
- the Employment Network could potentially have the 60 months of payments spread out over fourteen years from the time the EN first starts working with an individual.

⊙ People with disabilities use work incentives such as Plans for Achieving Self-Support (PASS) or Impairment Related Work Expenses (IRWE) that help people with disabilities pay for items and services related to employment. As a result of these work incentives, part of an individual's income will not impact their social security check. The regulations do not appear to adequately address the impact of work incentives on payments to the Employment Network, effectively increasing the amount an individual would need to earn before the Ticket would pay off for the employment network.

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Note: This is part 1 of a two-part article. Part 2 will appear in the March issue of TASH Connections and will include TASH's concerns and recommendations regarding the Ticket to Work and Work Incentives Improvement Act Proposed Regulations.

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THE TICKET TO WORK: A TOOL INTENDED TO INCREASE CONSUMER CONTROL OVER EMPLOYMENT SUPPORTS

Continued from page 17

RESOURCE LIST

For further information on the Ticket to Work and Self-Sufficiency Program and regulations, contact:

Geoffrey Funk, Team Leader, Legislative Implementation Team, Office of Employment Support Programs,
Social Security Administration,
6401 Security Boulevard,
Baltimore, MD 21235-6401; Voice: (410) 965-9010; TTY: (800) 988-5906; Web site: www.ssa.gov/work

Text of the regulations:

The Ticket to Work and Self-Sufficiency Program: Proposed Rule; Part 411 of Title 20 of the Code of Federal Regulations [20 CFR Part 411]; Federal Register, December 29, 2000. Available on-line at: <http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=2000_register&docid=fr28de00-45>

Related publications available from the Institute for Community Inclusion <www.childrenshospital.org/ici/publications/policy.html>

The Proposed Ticket to Work Regulations (Tools for Inclusion, Vol. 9, No 1, January 2001).

Proposed Regulations Implementing the Ticket to Work and Self-Sufficiency Program (Vol. 3, No. 1, February 2001, 12pp.)

The Ticket to Work and Self-Sufficiency Program and Established Under the Ticket to Work and Work Incentives Improvement Act of 1999. (Vol. 2, No. 2, February 2000, 4pp.)

Improvements to the SSDI and SSI Work Incentives and Expanded Availability of Health Care Services to Workers with Disabilities under the Ticket to Work and Work Incentives Improvement Act of 1999. (Vol. 2, No. 1, February 2000, 8pp.)

These publications are available via the ICI web site at <www.childrenshospital.org/ici/publications/policy.html>

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> *"The writer, Victor Hugo, said that when people dream together, they create a shared future. To Hugo, this meant far more than daydreaming. It meant grappling with the challenges and injustices of life, to create a better tomorrow, a richer world of opportunity for all people.*
>
> *This has been the critical work of this conference, and it must continue to be the work we all do, each in our own ways, long after we leave here.*
>
> *The declaration we have just heard outlined must guide our collective efforts. Like all declarations, it is a call to return and recommit to first principles, the fundamental principles of justice and equal opportunity.*
>
> *We must translate the language of self determination into a far more common and universally understood, language of human freedom, which I believe all people and most governments throughout the world, not only understand, but actively seek to embrace.*
>
> *We need to recognize, and help everyday people and our governments, recognize that this thing, that some call self determination, is not new. It is ancient. As ancient as the human will to live free."*
>
> ~taken from Bob Williams' closing address, which followed the presentation of the Declaration. The full speech is included in the report.

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Securing The Future for People with Disabilities

BY AL ETMANSKI

For the first time in history, individuals with disabilities are outliving their parents. Advances in medical technology, improved health care availability, higher social expectations and community living have ensured a longer life for our friends and family members with disabilities. In the next decade close to 6 million families in North America will be caring for their aging relatives with a disability.

My daughter, Liz, is a good example. Before she was five years old, she had had two life-saving operations that were not available five years previously. Nowadays, individuals with Down syndrome are living on average into their 60s. Compare this with an average of 9 years of life in the 1920's and 30 years in the 1960's for individuals with Down syndrome.

The immensity of this fact is slowly creeping into our consciousness within the disability community, and will soon command the full attention of government policy makers and even the corporate sector. This demographic trend, however, simply underscores a worry and anxiety that perches on the shoulders of parents the world over from the moment our children are born. "What will happen to my son/daughter with a disability if something should happen to me?" is a constant concern confronting all parents at the best and worst of times.

Thinking about the future is a natural extension of being a párent regardless of the age of our children. As one parent in Australia recently commented, "I need a 'drop dead' plan." And, as we all know, although many of us prefer to ignore it, growing old is not a certainty for any of us.

As more and more individuals enjoy their senior years, pressure is exerted on our systems and institutions to respond. This, in turn, has the benefit of raising awareness on the importance of planning for the future for our sons and daughters with disabilities regardless of their age (or our age, for that matter).

Creative Responses are Emerging

Fortunately, families everywhere are developing creative responses to what some people have described as "aging anxiety." And the solutions are emerging from the age group one might expect - parents who, in their senior years, are forced to confront their own mortality. These families, many of whom were leaders in the community-based disability movement which emerged after World War II, are not content just to resolve their own future planning challenges. They are passionate about sharing their pioneering efforts with younger families. We will all benefit from their living legacy.

I work for one such group, the Vancouver, Canada-based Planned Lifetime Advocacy Network (PLAN). In 1989 a small group of 15 families, average age 70, came together to help each other answer the stark question, "What will happen to our sons and daughters with disabilities when we die?" They created an organization as a container for their worries, their dreams and their solutions. Little did they know they had stumbled into an area families and caregivers everywhere were struggling with. The content of this article has been distilled from PLAN's experience and direct contact with over 10,000 families in the ensuing years.

From a general perspective, families report three lessons which emerge once they embark on the path of preparing for their own death and planning for the future well being of their relative with a disability. These are worth remembering as you read the 7-step overview presented here.

1. The most important consideration is not how long you will live, but how well you will live your life. In other words exploring the dimensions of "a good life" is the key challenge.

2. Planning for the future is the best excuse for changing the present.

3. Wills, estate planning and trusts are mere utensils, not the meal.

Respecting the choices and preferences of our relatives while at the same time ensuring their safety can be a tough balancing act. Legal guardianship has always juggled autonomy – respecting the choices of individuals with disabilities – with protection. The result, unfortunately, is usually over-protection. However, efforts to change this are underway in many jurisdictions.

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Seven Steps to Creating a Plan for the Future

Fifty per cent of North Americans die without a will. Ninety per cent of the heads of family-run businesses die without a viable estate and succession plan. Clearly, thinking about our own death, let alone preparing for it, is something most of us would prefer to avoid. The added dimension for families who have relatives with disabilities is they must create a plan not just for their own lifetime but also for the lifetime of their relative.

The following seven steps represent the key elements in creating a plan for the future. Each is important and will move you along the path. Taken together they represent a holistic and comprehensive approach to creating a safe and secure future and a good life. You will be able to create a checks and balance system that recognizes the best any of us can do is to be well prepared for the future, not attempt to predict it.

Step One:
Clarifying and Sharing Your Vision

As the old saying observes, "If you don't know where you are going any road will get you there." Families have definite dreams and yes, nightmares when they think about the future of their loved ones. We have learned to use both our love and our fears as motivating forces for clarifying our vision for the future. The trick is to release them from our silent consciousness and share them with others who care about our relative with a disability. We often ask families to make two lists, one describing a perfect day in the future, and the other describing their worst nightmare.

We have also learned not to ask, "What program or service do you want for your son/daughter?" That question simply invites program and service answers which restrict the vision. Instead we ask, "What might a good life be?" Those answers abound with eloquence and often poetry. Emotional, spiritual and social considerations take precedence and services fade into a supplemental role. Answers to the "good life" question invariably fall into the following categories:

Our vision of a "good life" for our relative with a disability might include:

a. Being surrounded by friends and family members
b. Living in a place of one's own
c. Contributing to one's community
d. Having one's choices respected
e. Enjoying financial security

Clarifying a vision for the future would remain an artificial exercise unless one:

▶Includes your family member with a disability in the process

▶Shares the results with other members of the family and your son/daughter's personal network

▶Trusts in the possibilities for the future for your relative

▶Is prepared for a few surprises

Step Two:
Nurturing and Consolidating Relationships

Billie Holiday sang it best, "Without friends I ain't got nothin." To be isolated is an enormous tragedy and as Mother Teresa observed, "a most terrible poverty." Loneliness may be the most significant handicap experienced by our friends and family members with disabilities. This loneliness becomes even more disturbing when one contemplates the time when we are gone.

It doesn't matter how much money we leave in a special needs, discretionary trust, or how well written our will is. Without friends our family member could be cast adrift in a very impersonal service delivery system after we are gone. Readers of TASH Connections are well acquainted with the social and health benefits of relationships. Supportive social ties reduce the likelihood of illness, aid the healing process, improve our immune system and are the most effective means for ensuring a good and safe life for individuals with disabilities. All other approaches are secondary.

It should go without saying yet it bears repeating: No disability precludes relationship. Parents can often lose sight of this. We have discovered that not only is it important for our family member to be in relationships with several people, but also it is equally important to connect these people with each other. Formalizing these connections into a Personal Network or Circle of Support provides:

- Companionship
- Sharing of responsibility among brothers, sisters, friends and supporters
- Advocacy and monitoring of the formal programs and services your relative receives
- A potential source for executor and trustees
- A vehicle for addressing your hopes and dreams
- Continuity after you are gone

Step Three:
Living in a Place of One's Own

The value of home is universal. Our home is our haven, our place of refuge. It is where our authentic self emerges. Home is where we can truly "be," offering hospitality, relishing privacy, enjoying intimacy. Unfortunately, many people with disabilities live in houses that are essentially organized as places of work for staff; houses devoid of the little things that make a place a home. Group homes for example, excel at providing a place to eat, sleep and be

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Securing The Future for People with Disabilities

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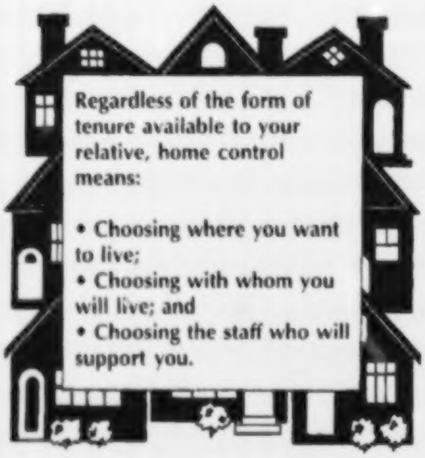
sheltered. Often they do not reflect the relatedness of people, places and things. They do not nurture relationships among the people who live there, or help them understand their connection with nature or with the everyday things they use.

Getting from "house" to "home" can be challenging for our friends and family members with a disability. One approach is home ownership. The National Home of Your Own Alliance has the best material on accomplishing this dream. There are, however, other means to create control over the housing environment in which your relative chooses to live. These include long-term leasing, co-housing, housing equity coops, and land trusts.



Regardless of the form of tenure available to your relative, home control means:

- **Choosing where you want to live;**
- **Choosing with whom you will live; and**
- **Choosing the staff who will support you.**

Creating a home cannot be done in isolation from the other steps discussed here. Without the existence of a Personal Network, our sons and daughters will be just as isolated in their own place as anywhere else. Similarly, your will and trust agreement will formalize arrangements for housing tenure and maintenance. For example, a home may be owned by a trust. Step 5 provides some options for protecting your relative against exploitation and to assist them in making housing-related decisions.

Step Four:
Making a Contribution

Each of us has a deep longing to give, to contribute, to offer and to share what is meaningful to us. Unfortunately, this is often an experience denied to our friends and family members with a disability. There are at least two reasons for this tragic oversight: there is no recognition they have something to contribute; and they have little opportunity to make their contribution.

A good life, now and in the future, for our daughters and sons with disabilities means:

- Believing they have a gift
- Validating their gifts
- Assisting to develop their gifts
- Ensuring their gifts are given

Contribution establishes the valued role of citizen. The next leap forward for the disability community will be made from the base of citizenship. Citizenship is about both rights and obligations and obligation is about contribution. People with disabilities are an underutilized resource in our community and their contribution, whether paid or unpaid, is an important source of "social capital" - the glue that holds our communities and neighborhoods together.

Step Five:
Ensuring Choice

Respecting the choices and preferences of our relatives while at the same time ensuring their safety can be a tough balancing act. Legal guardianship has always juggled autonomy — respecting the choices of individuals with disabilities — with protection. The result, unfortunately, is usually over-protection. Efforts to change this are underway in many jurisdictions. These were well-described in Dohn Hoyle and Kathleen Harris's article, *Re-thinking Guardianship*, which appeared in the November 2000 issue of the TASH newsletter.

> Ensuring choices for individuals with disabilities means creating a process for supported or joint decision making. When combined with a Personal Network and individualized funding, there is greater likelihood their choices will not only be heard but heeded.

In general, families would be advised to examine supported decision making as an alternative to formal guardianship. Supported decision making provides a way to respect the unique decision making style of each individual with a disability and to provide support where necessary without depriving the individual of his/her legal decision making rights.

Supported decision making for our relatives and friends with disabilities means:

- They are an active participant
- All methods of communication are taken into consideration
- Their tastes, preferences, intuition, motives and ability to discriminate are respected
- Trusting relationships have as much weight as intellectual ability
- The focus is on abilities
- They are surrounded by caring, knowledgeable and trusting people who are in a relationship with them
- Risks, failures and mistakes are recognized as learning opportunities

Many families and friends are developing a Supported Decision Making Agreement which identifies individuals who are available to assist with decision making in the areas of medical/health; financial; and daily living. These agreements are recognized legally in some jurisdictions and are having the force of moral authority in others.

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Securing The Future for People with Disabilities

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Ensuring choices for individuals with disabilities means creating a process for supported or joint decision making. When combined with a Personal Network and individualized funding, there is greater likelihood their choices will not only be heard but heeded.

Step Six:
Designing a will and estate plan

A will and estate plan is one of three potential sources of wealth for individuals with disabilities. The other two are the income they receive from work and the individualized funding they receive from the government.

A will and estate plan is the means by which parents can leave a share of their wealth to their child with a disability. There are some critical considerations to address, the two most important being:

1. *Write a will.* If you do not have a will, the government will distribute your assets according to a formula they devise. Similarly, they will determine who will care for your minor children and it may not be whom you want.

2. *Establish a 'special needs' or discretionary trust.* These trusts enable individuals with disabilities to receive their share of the estate left on their behalf without jeopardizing the benefits they receive from the government.

The more friends and supporters your relative with a disability has, the greater the possibility of "humanizing" your will and estate plans. For example, if you choose a corporate trustee to manage, invest and disburse money from a trust fund you establish, assuming they are likely to know very little about your family member. We recommend families consider nominating two trustees, at least one who has a personal connection to the family member with a disability. A good source of trustees is the Personal Network. You can advise your trustees to seek advice from the Personal Network members before spending from a trust. Finally, you can instruct your trustees to check directly with your son or daughter before making any financial decisions.

Step Seven:
Securing your plans

If a family has followed the previous steps they have:

- clarified their own thoughts for their relative with a disability and shared with others these hopes and dreams
- developed or formalized a network of support
- built a vision of home and contribution
- developed a supported decision making agreement
- and created a will and estate plan.

These plans by themselves will definitely ensure the safety and well being of your family member with a disability. Nevertheless, more and more families are going one step further. They are creating a new type of organization to provide two main services:

1. To assist families of all ages to develop their plans while the parents are still alive

2. To monitor and safeguard these plans when the parents become incapacitated or die.

Planned Lifetime Advocacy Network (PLAN) and similar organizations can be used by families to:

- Provide advice to executors and trustees
- Maintain the health of the individual's Personal Network
- Monitor and advocate for improved services and programs
- Oversee supported decision making arrangements
- Keep in regular and direct contact with the individual with disability
- Respect and carry out specific wishes of the family
- Provide continuity

Typically these organizations are independent of the service delivery system and independent of government funding. This ensures their objectivity and effectiveness as an advocate and monitor. These organizations are family-controlled and directed and become the eyes and ears, arms and legs of the parents after the parents are gone. In many ways, these new groups are revitalizing the family arm of the disability movement. Families are discovering what they already knew — together they are better.

Conclusion

The good life paradigm represents a new way of thinking and acting about the life we want for our loved ones with disabilities. In a paradoxical but wonderful manner, a good life framework actually makes a difference now, not only for our relatives with disabilities but also for their parents. In that regard future planning is less about the future and more about peace of mind, now!

Al Etmanski is the Executive Director of the Planned Lifetime Advocacy Network (PLAN). He also serves on the faculty of John McKnight's Asset Based Community Development Institute. He is the author of numerous articles and the books, Safe and Secure - Creating a Personal Future Plan For People with Disabilities and A Good Life - For You and your Relative with a Disability.

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PLAN's web site is <www.PLAN.ca>

References:

National Home of Your Own Alliance - <http://alliance.unh.edu>

You Can Count on Us

BY VICKIE CAMMACK

Michael is a ham. He loves being the center of attention. These days he's a far cry from the abrupt, reticent, and withdrawn man of ten years ago. If only his mother could see him now. Her faith in the power of relationships would not be misplaced.

Tonight he is giving a workshop. The co-presenters and Michael meet beforehand. The topic is 'Personal Networks - Weaving the Ties That Bind.' They agree on a format. Vickie will assume the role of a television personality and interview Michael.

Michael is excited. A real television-style interview. No detail is too small. It must be authentic, for a man who is precise. It must be Oprah, not Rosie. There must be a microphone. There must be an elevated stage. Everyone agrees. They go along with the illusion.

Seventy-five are in attendance. There is a camera crew from the local community college. The workshop is being taped for distribution.

The moment arrives and Vickie as Oprah turns to ask Michael her first question.

"Hold everything," shouts Michael. "Let's get rid of these extra chairs." The chairs are removed.
Then, nodding to the camera operator, he asks if they have enough light. They do, but thank him for asking. Michael, clearly, is the one in control.
Next comes a sound check. You can never be too sure!

Vickie tries again. By now the audience is into the spirit of the occasion. "Let's go, Rosie," they chant encouragingly. "No, no," interrupts Michael. "Not Rosie but Oprah. Oprah Winfrey." "Yes," says Vickie, "Oprah would like to ask you a question."

"Wait a minute," says Michael forgiving her indiscretion, "You've got to start properly." "Lights, camera, action," announces Vickie, clapping her hands to simulate take seven. "And now, here's Michael."

Everyone is finally satisfied, particularly Mcihael. The interview can begin. He handles the preliminary questions with aplomb. Next comes a more personal question.

"Tell me, Michael, what does your network do for you?" "They give me hope, love and encouragement which I really need now that my mother is dead and gone up to heaven." You could hear a pin drop. It was worth the wait.

Michael's mother, Marie was a courier de bois. This is a French term for the early Canadian explorers who cut, punched and hacked trails through our country's dense forests. In Marie's case she was blazing a trail to the future. She knew her health was declining. She quickly cut through the details of wills, estates, trusts and lawyers. She then found herself alone on the precipice with Michael. There was a large summit ahead of them. She knew Michael would be alone in the world without her. It was at this point that she and Michael decided to actively create a personal network or circle of support for Michael. The story at the beginning of this article illustrates the discoveries of their final journey together. Marie has passed away and Michael certainly misses her. But as Michael says so poignantly, he has a network of people to give him love, encouragement and support.

Michael's comments begin to illustrate what personal networks mean for the people at the center of them, especially when their parents die. I work for PLAN (Planned Lifetime Advocacy Network). We support individuals with disabilities and their families to take the trek to the future. Early on in our work with Marie, Michael, and our other founding pioneers, we realized there would be no future, or at least not a future anyone wanted, if friends and family were not a part of it. We also realized that the vast majority of folks who were coming to us were, like Michael, very isolated, especially in terms of friendship.

We determined that actively and strategically facilitating relationships had to be a key element of preparing for the future. We also learned very quickly that of course, friendships are key elements of having a life in the present. In fact, many of the folks at the center of PLAN's personal networks would equate getting a network with, in today's vernacular, getting a life.

At PLAN we like to focus on the future by thinking about what constitutes a good life. Personal networks contribute to what virtually all us of would call a good life in five very compelling ways. Clearly, as Michael states above, having a group of friends and supporters provides the emotional support and encouragement that each of us needs. Personal networks also provide practical, hands-on assistance with the tasks of daily living. Perhaps less well known, however, is that personal networks play a crucial role in the health, the wealth and ultimately in the citizenship of people with disabilities in our communities.

The following paragraphs illustrate how personal networks make a difference in each of these five areas now and in the future.

Emotional Support

This is probably the area most us of think of when it comes to friends and families. Most of us cannot imagine

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You Can Count on Us

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life without our friends to share our joys with when times are good and to lean on when times are tough. PLAN's personal networks have been great sources of encouragement for the people at the center of the networks. There is nothing like having a group of people who believe in you when it comes to gathering up the courage to take on a new challenge. Our networks have been bolsters for folks bracing themselves to start a new job, go back to school, or even to simply meet a new person. The emotional support of network members has been the catalyst that has liberated folks to see themselves as competent and capable of achieving their dreams.

We also have seen our networks walk with people through traumas such as substance abuse, episodic mental illness and personal loss. For example, when George's mother became ill with cancer his network knew he would need a lot of support in preparing for her death. They collaborated with George to create a video of his mother's life. When she did pass away this amazing group of men and women adopted the motto 'never alone.' And, indeed, George was never alone for the first month after his mother's passing. A few months after his mother's death George was able to say, "My mother has died and I miss her. But with the help of my network I'm doing o.k."

The contributions of people who have been labeled as disabled have never been more needed. Providing the opportunities for these contributions to be made by ensuring that a personal network of friends is there to receive them is one of the most profound legacies a future plan can create.

Practical Assistance

Most families in preparing for the future are acutely aware of the innumerable things, small and large, they do on behalf of their relative. These can range from filing income tax returns to buying the best-fitting brand of underwear. It is often these personal details that families are the most uncomfortable leaving to individuals who are paid to support their relative. Personal network members at PLAN provide a vast array of practical support to their friends.

Network members are the ones who notice if the coat is getting threadbare and make a quick trip to the mall. They help write holiday cards, make sure the neighbors are happy, and that the doctor's instructions are followed. They have even been known to clean the toaster and take the cat to the vet. In short, while we all know a personal network can never replace families, they are the next best thing.

Staying Healthy

One of the issues families are most concerned about in thinking about the future is the health of their relative. Painstaking and important work is often done by a family to make sure all the details of medical treatment over the years are documented and shared. Clearly having a network member in the know is critical to communicating with the medical establishment to ensure the best treatment is received.

There is, however, another often overlooked role that personal networks play in safeguarding the health of the person at the center. There is a burgeoning field of research called pycho-neuro-immunology. This field explores the mind-body connection in health. The results of this research are conclusively pouring in. When we have a supportive social network we all live longer, get sick less often and heal more rapidly if we do become ill. The old maxim holds true: a good friend is the medicine of life. Ensuring there are involved friends and loved ones is a crucial task for any family worried about their relative's health in the future.

Wealth and Social Capital

Planning for the future always involves some discussion about financial resources. Certainly having adequate income is a critical element in anyone's future. What we have discovered at PLAN though, is that money alone can't buy happiness or success. Of course, we knew this when we began our work, but initially the seductive power of finance had us thinking that wills and estates were the most important things to be addressed in future planning. They seemed so concrete and practical and, frankly, easy in comparison with the intangible world of relationships. Interestingly, the concept of social capital has recently emerged and it is beginning to put value on the often difficult-to-measure assets of relationships.

Social capital is both the number of relationships we have and the trust, reciprocity, and shared values in those relationships. Our supply of social capital directly impacts our choices and opportunities. Research about social capital is finding among other things, that when we have a good stock of it our job prospects increase, our ability to learn is improved, and our safety is enhanced.

Alternatively, when individuals or groups are found to be lacking in social capital their locus of control is diminished and clientele-ism increases. Social capital could be considered the most important source of wealth a person with a disability has. Creating a personal network represents a strategic and focused way for families and individuals to increase their social capital.

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You Can Count on Us

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Contribution Equals Citizenship

It is fair to say that the term citizenship does not often come up when working with families and individuals to plan for the future. Instead, they use phrases like doing something meaningful, having a reason to get up, being valued, and making a contribution. When you think about it, aren't giving, contributing, and making a difference all at the very heart of citizenship? At PLAN we believe contribution equals citizenship.

People with disabilities, along with other marginalized groups, have made enormous strides in securing their rights in the past two decades. The battles won, the laws passed, and the policies written have all been extremely important on the road to citizenship. Perhaps for people with disabilities, they represent the first half of the road. It is the other half of the path to citizenship — not rights but obligations or contributions — that needs to be traveled now.

Relationships are the ticket to the contribution side of the journey to citizenship. As seen above, social capital can certainly help to secure employment if that is the main path to contribution. But there are many other unique and crucial contributions that people with disabilities can make.

Time and again network members tell us that their friendship with the person at the center of the network contributes to them seeing their own life as more meaningful. They say things like, "Her presence grounds me. It is a real gift since I get so caught in the doings of life." And, "He reminds me that we all have needs for each other that we don't even realize." Network members use words like inspiration, courage, and creativity when they are speaking about what they receive from their relationships with people with disabilities.

Someone once said a vocation is where our deep gladness and the world's deep hunger meet. Surely most of us are hungry for meaning in our lives, surrounded as we are by today's culture of individualism and greed. The contributions of people who have been labeled as disabled have never been more needed. Providing the opportunities for these contributions to be made by ensuring that a personal network of friends is there to receive them is one of the most profound legacies a future plan can create.

For the people at the center of a personal network, contribution of their unique gifts equals the living of a life of meaning. For the rest of us, the privilege of receiving these gifts equals an opportunity to become our most human.

Vickie Cammack is a co-founder of PLAN and the Executive Director of PLAN Institute for Citizenship and Disability. She developed and directs PLAN's Personal Network Program and assists communities internationally in their efforts to develop similar organiztions. She is co-author of "Safe and Secure - Six Steps to Creating a Personal Future Plan for People with Disabilities." She can be reached at vcammack@plan.ca

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Living A Self Determined Life

Continued from page 14

advocacy or self advocates, we wouldn't have self determination. I worry sometimes that professionals want people to gain self determination so bad, they forget to include us in the self determination process.

A lot people without disabilities will often say that self determination can only be achieved by the "chosen few." What I think they mean by that is that my friends and I can achieve self determination because we have jobs in the community and we are "smart enough" to handle our own lives. However, people think that people who use wheelchairs or have "severe" disabilities can't ever gain self determination.

I would argue this point because I have seen people gaining self determination for themselves. I have a friend who has a "severe" disability and he needs 24-hour support. He lives in his own home. He also makes his own decisions with support from his family and friends.

I am really enjoying my life. I believe without self determination I couldn't do as much as I am doing today with my life. I also believe that people are truly happier with their lives than they were 40 or 50 years ago when they lived in institutions, or even 10 years ago when many lived in group homes where they were controlled by others.

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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VOLUME 27 • ISSUE NUMBER 3/4 • MARCH/APRIL 2001

TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- The Path to Community Participation
- Essential Lifestyle Planning
- Developing Partnerships between Researchers and Culturally Diverse Families
- Permanency Planning for Children with Developmental Disabilities
- The Convention on the Rights of the Child

FAMILIES
PLANNING
TOGETHER

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.

From the Editor

The debacle that became the 2000 presidential election notwithstanding, it is time once again to turn our attention to a selection process in which TASH members can have full faith – the election of new members to the TASH Executive Board.

Nominations to this year's slate of candidates are encouraged. Members are also welcome to self-nominate. Nomination guidelines, along with information on the responsibilities of serving on the TASH Executive Board, may be obtained by contacting TASH's Executive Director, Nancy Weiss, at (410) 828-8274, ext. 101, or you may send an e-mail to nweiss@tash.org.

Nominations can be made by mail, fax (410-828-6706) or e-mail, and must be received by **June 8th.**

Priscilla Newton

WHOM DO I CONTACT??

- ☐ **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- ☐ **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- ☐ **For questions about the 2001 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- ☐ **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- ☐ **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
- ☐ **For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- ☐ **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- ☐ **Don't forget to visit TASH's web site at http://www.tash.org**

The TASH Newsletter is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in the TASH Newsletter should be sent to: TASH Newsletter, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Newsletter Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org

TASH: Public Policy In Action

The Extended Employment Regulation finalized by the Rehabilitative Services Administration in January has been earmarked for "review" by the Bush Administration.

TASH, in coalition with the Association for Persons in Supported Employment (APSE) and other progressive advocacy organizations, strongly support the Rule because it would, 1) limit Title I funding for "extended employment" (sheltered workshops) to short-term training activities leading to integrated employment, and 2) clarify that the only acceptable employment outcomes for Title I are in integrated settings -- settings that are "consistent with the individual's strengths, resources, priorities, concerns, abilities, capabilities, interests and informed choice."

Opponents of the Rule argue that it removes choice from individuals who wish to remain in sheltered workshops.

TASH and APSE know that this Rule will actually ensure choice for individuals whose job placement decisions have too often been made *for* them, based on their disability rather than their abilities and personal interests.

When individuals are provided customized supports and employment that addresses their interests and capabilities, the vast majority express satisfaction with, and preference for community jobs.

TASH members are long-time advocates for integrated employment, and should immediately write to Education Secretary Rod Paige asking for the release of **The Final Rule for the State Vocational Rehabilitation Service Program** (34 CFR, Part 361). Letters should be sent to:

Secretary Roderick R. Paige
U.S. Department of Education
400 Maryland Avenue, SW
Washington, D.C. 20202-0498

* * *

The General Accounting Office has released a report to the U.S. Senate and House of Representatives presenting the results of their findings regarding the impact of the disciplinary provisions of **The Individuals with Disabilities Education Act Amendments of 1997** (IDEA 97). They found special education students who are involved in serious misconduct are "being disciplined in a generally similar manner to regular education students." Moreover, principals reported that IDEA plays a limited role in affecting schools' ability to "properly discipline students," and that the combination of federal and local policies governing special education had a "positive or neutral effect on school safety and orderliness."

Nonetheless, principals still maintain that "a separate discipline policy for special education students is unfair to the regular student population." In addition, principals found the procedures for IDEA are burdening and time-consuming. The full report, **"Student Discipline: Individuals with Disabilities Education Act,"** is available at http://www.gao.gov.

* * *

The American Bar Association has voted to oppose schools' **"zero tolerance" disciplinary policies**. The House of Delegates adopted the resolution against current disciplinary policies in public education because they "fail to take into account the circumstances or nature of an offense or an accused student's history."

In taking this action, the ABA supported the following principles concerning school discipline:

- Schools should have strong policies against gun possession, and be safe places for students to learn and develop;
- In cases involving alleged student misbehavior, school officials should exercise sound discretion that is consistent with principles of due process and considers the individual student and the particular circumstances of misconduct; and
- Alternatives to expulsion or referral for prosecution should be developed that will improve student behavior and school climate without making schools dangerous.

To read the resolution and the report on **Zero Tolerance**, visit the American Bar Association's web site at www.abanet.org

* * *

Help to promote the TASH values of inclusion and quality of life for all people by becoming an active member of the TASH Government Relations committee. For more information about the Committee's work, or to join the listserve, contact Jamie Ruppmann, Director of Governmental Relations at (410) 828-8274, ext. 104 or send an e-mail to jruppmann@tash.org

Join the TASH Governmental Affairs ListServe Today!

To sign up, go to TASH's site at http://www.egroups.com/subscribe/TASHGovAffairs

The article, *"The Ticket To Work: A Tool Intended to Increase Consumer Control over Employment Supports,"* which appeared in the February 2001 issue of TASH Connections, provided a summary of the Ticket program, based on the proposed regulations published in December 2000.

The following excerpts are from a letter submitted by TASH, under the auspices of the TASH Employment Committee, to William A. Halter, Acting Commissioner of the Social Security Administration, citing TASH's concerns that the proposed regulations fall far short of meeting the requirements of individuals with the most intensive support needs.

To obtain a complete copy of TASH's comments, contact Nancy Weiss at 410-828-8274, ext. 101, or nweiss@tash.org

February 22, 2001

Consistent with the mission of TASH, these comments focus on the effectiveness for all individuals with disabilities who receive cash benefits under the SSI and SSDI programs, with particular emphasis on the effectiveness of the regulations as a change agent for individuals with the most significant disabilities.

Congress specified that a goal of the [Ticket] legislation is to enable individuals with disabilities to "reduce their dependence on cash benefit programs." While the proposed regulations establish a broad framework for implementation of this legislation, their effectiveness in expanding employment opportunities for all individuals with disabilities must be measured against three fundamental questions:

(1) Do the proposed regulations provide sufficient incentives to Employment Networks to be a meaningful tool for individuals who have significant disabilities and significant employment support needs?

(2) Are the proposed regulations sufficiently simple in their design to make them easily understood by SSI and SSDI recipients, and to be easily administered by Employment Networks and the Program Managers?

(3) Do the regulations meet the stated intent of the regulations by both eliminating and reducing cash payments to SSI and SSDI recipients?

As proposed, the regulations — which are complex and difficult to understand for both beneficiaries and for Employment Networks — do not pass the test provided by these questions. The recommendations below reflect specific concerns that individuals with the most intensive support needs, individuals who are likely to be beneficiaries under the SSI program, will receive tickets with the lowest cash value.

Concerns and Recommendations

The program provides insufficient incentives for the employment of individuals on SSI, representing many individuals with the most significant disabilities.

Overall, the proposed value of the Ticket for SSI recipients does not provide sufficient incentive for Employment Networks to serve SSI recipients and individuals with more significant disabilities. Despite the lower payment levels, individuals on SSI will typically need to reach higher levels of income before an Employment Network can receive a payment.

Recommendations:

- Establish demonstration projects that assess the impact of higher levels of payment to Employment Networks for SSI recipients.
- Equalize the level of income that triggers Ticket payments across the SSI and SSDI programs by using income at the SGA level for both programs. This will also dramatically simplify the regulations, making the program more understandable for recipients and easier to manage for Employment Networks and the Program Manager.

The Milestone Payment system does not sufficiently address the up front costs for Employment Networks, particularly for individuals with significant disabilities.

The purpose of the Milestone payment System is to ensure that the Ticket benefits all beneficiaries, including those with significant support needs such as pre-employment costs related to career planning, job development, and initial on-the-job support. The milestone payments proposed are both too small to address these concerns, and occur too late in the employment process to meet the needs of the small- and medium-sized organizations that have historically achieved the highest level of success in supporting difficult-to-serve individuals.

Recommendations:

- Increase payments under the outcome system to at least 38% of the average monthly payments under both SSI and SSDI.
- Establish milestone payments earlier in the employment process, recognizing the intensive expenses incurred during career planning and job development.
- Simplify the payment structure by providing the same level of reimbursement for each monthly outcome payment.
- Increase the level of early payments to Employment Networks by paying a higher percentage of the total 60-month SSA savings in the milestone payments, and reducing the monthly outcome payments.

The regulations need to clarify impact of other Work Incentives on Ticket payment.

Existing work incentive programs, including PASS and Impairment Related Work Expenses, have been a meaningful tool for many individuals with disabilities. While these work incentives have not been used widely enough, the Ticket regulations should be clear about how they interact with outcome and milestone payments under the Ticket.

Recommendations:

- Clarify the impact of participating in the PASS and IRWE work incentives on the calculation of when outcome payments begin.

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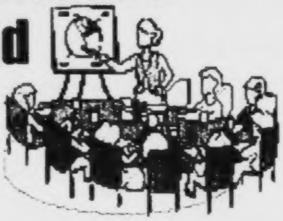
Want to Learn New Things But Don't Have Time or the Budget to Attend A Conference?



TASH Teleconferences Are For You!

Upcoming Events

Series on Positive Behavior Supports in Schools

- **Functional Assessment** ~ facilitated by Tim Knoster, *Ed.D. Division of Applied Research & Education Support, Dept. of Child & Family Studies, University of South Florida*

- **Designing Positive Behavioral Intervention** ~ facilitated by Tim Knoster, *Ed.D. Division of Applied Research & Education Support, Dept. of Child & Family Studies, University of South Florida*

- **School-Wide Behavior Support Plans** ~ facilitated by Rob Horner, *Ph.D., Professor of Education at the University of Oregon, Director of the Specialized Training Program, Department Head of the Department of Special Education Community Resources*

Transition and Adult Issues

- **Post Secondary Education: A Choice for Everyone** ~ Facilitated by Carol Tashie, M.Ed., Technical Assistance Coordinator, UNH, Institute on Disability UAP

- **Integrated Affordable Housing in Light of the Olmstead Decision** ~ facilitated by Jay Klein, *UNH Institute on Disability and Center for Housing and New Community Economics (CHANCE)* and Mike Auberger, *ADAPT and Center for Housing and New Community Economics (CHANCE)*

The cost to participate is only $45 per telephone connection, per session. Information about dates, times and other details on these exciting teleconferences can be found at <www.tash.org>, or by emailing: dmarsh@tash.org, or calling 1-800-482-8274 ext. "O"

TASH Awards

It's time once again to submit TASH Award Applications!

This year at the annual conference, in addition to the Alice Hayden and Thomas Haring Awards, TASH will confer a special series of awards around the theme of this year's TASH conference. These awards will honor the groundbreaking and exemplary work of individuals and companies to create and promote positive images of people with disabilities. Image Award recipients will be honored at a special Showcase of Images Reception on Thursday evening, November 15th.

To nominate an advertisement, commercial, television show, movie, publication, artist, or any medium you think has met the criteria listed here and has made significant impact on the positive images of people with disabilities, send full details regarding the nomination, including name(s) of the company or individual; complete contact information; and specific details of the work for which the individual or company is being nominated (include a sample or copy where possible).

This is your chance to honor such accomplishments with official recognition. Please take the time to submit an application. Awards will be conferred as part of the TASH Annual Conference to be held in Anaheim, November 14-17, 2001 Award applications will be accepted through July 1, 2001. Please be sure to indicate for which award you are applying on the application, and submit all required documents or information requested for that award.

2001 Alice H. Hayden Award

This $500.00 cash award will be presented to a doctoral student enrolled in a program in education or a related field and who demonstrates potential for leadership in teaching, scholarship, and service on behalf of people with significant disabilities. The individual needs to have demonstrated a continuing desire in working in partnership with people with disabilities.

2001 Positive Images Awards

This award honors presentations in print, film or other form of media, which promote the positive images of people with significant disabilities in all aspects of community life. Criteria for selection include: high quality, accuracy of information, meaningfulness of subject matter, degree of impact, and promotion of positive images of people with disabilities.

2001 Thomas G. Haring Award for Research

This $1000 cash award is presented to promote research and scholarly activity in the field of significant disabilities. The award will be presented to the author(s) of a study of particular significance that was published in JASH within the two years prior to the annual conference. The study will have demonstrated scientific merit, and have made an important contribution to the disability field.

NOTE: Other awards may be announced by individual committees.

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2001 TASH Award Application

- Applications due July 1, 2001 -

How to Apply:

(1) Complete this application form - front and back- as fully as possible.

(2) Attach a brief narrative discussing why the nomination is being made. Please see the other side of this form for a list of supporting information and materials that must be submitted for the particular award you choose below.

3) Please indicate for which award you are applying. **Check only one award.**

☐ Alice H. Hayden Award

☐ Positive Images Award

☐ The Thomas G. Haring Award for Research

(4) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than **July 1, 2001**. Send to:

Awards Committee
TASH
29 West Susquehanna Avenue
Suite 210
Baltimore, MD 21204

Person or Team Being Nominated:

Name of the Individual: ____________________

Street Address: ____________________

City: ____________________

State/Province: __________ **Country:** __________

Zip/Postal Code: ____________________

Daytime Telephone: (___) ____________________

Evening Telephone: (___) ____________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

Name of team members (more room on reverse side) ____________________

Street Address: ____________________

City: ____________________

State/Province: __________ **Country:** __________

Zip/Postal Code: ____________________

Daytime Telephone: (___) ____________________

Evening Telephone: (___) ____________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

Person Making the Nomination:

Name: ____________________

Relationship to the team/person: ____________________

Street Address: ____________________ **City:** ____________________

State/Province: __________ **Country** __________ **Zip/Postal Code:** __________

Daytime Telephone: (___) ____________________ **Evening Telephone:** ____________________

FAX:(___) ____________________ **E-mail:** ____________________

Please provide as much information as possible about the persons who are part of this team. Please use additional paper if necessary.

Name of Team Member: ______________________

Organization (if applicable): ______________________

Street Address: ______________________

City: ______________________

State/Province: ____________ **Country:** ____________

Zip/Postal Code: ______________________

Daytime Telephone: (___) ______________________

Evening Telephone: (___) ______________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member: ______________________

Organization (if applicable): ______________________

Street Address: ______________________

City: ______________________

State/Province: ____________ **Country:** ____________

Zip/Postal Code: ______________________

Daytime Telephone: (___) ______________________

Evening Telephone: (___) ______________________

Is this individual(s) a member of TASH?
☐ Yes ☐ No

***

Name of Team Member: ______________________

Organization (if applicable): ______________________

Street Address: ______________________

City: ______________________

State/Province: ____________ **Country:** ____________

Zip/Postal Code: ______________________

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3. Attach at least three (3) letters which support the nomination. These letters should be from professors who are familiar with your qualifications. The letters should present specific data or anecdotal information which convey an accurate picture of your current achievements and potential for significant contributions to the field.

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A Recovering Behaviorist

BY JIM McFALLS

"They just looked at him, smiling. And slowly, Harry looked into the faces of the other people in the mirror, and saw other pairs of green eyes like his, other noses like his, even a little old man who looked as though he had Harry's knobbly knees - Harry was looking at his family, for the first time in his life.

The Potters smiled and waved at Harry and he stared hungrily back at them, his hands pressed flat against the glass as though he was hoping to fall right through it and reach them. He had a powerful kind of ache inside of him, half joy, half terrible sadness."

J.K. Rowling, Harry Potter and the Sorcerer's Stone

Herb Lovett once told me that I was a "recovering behaviorist." He meant it as a compliment, and I have treasured that conversation over the years. I was struggling to find a way to help people with developmental disabilities and their families deal not only with challenging behaviors but also with the system that was supposed to be supporting them. The behavioral paradigm was what I had been taught and used for years as my way of facilitating behavior change. Now, it wasn't working for me. I was restricting people and punishing people and people weren't really changing. I was helping to set up unnatural, controlling environments that couldn't be sustained. A true believer, I had written behavior programs to stop people from drinking too much coffee, to eliminate rocking, to control aggression and to minimize hugging. I was leaving all of that behind and Herb saw that and helped me along the way.

Probably the most fundamental insight I came to was that behavior intervention is at least as much an art as it is a scientific endeavor. The more I had studied and utilized the science of applied behavior analysis and the more I was considered skilled at what I did by the people who used my help, the more I felt and acted like I was an artist. Although I use a broad variety of data collection strategies, tools, assessments and evaluations, it is what I do with all of those data that is the artistic part of me. I have to transform these data into something that is really useful and creates understanding.

Everyone has "filters" that they use to process and understand the perceptions they receive from their senses. The filters that I have developed include the "positive approaches" and "general systems" types. When I look at a "behavior problem" I begin thinking of questions that have to do with the environment the person is engaged in, what forces are impacting on the person, who the other people in the person's life are and so on instead of the frequency, intensity and duration of the behavior and how can I decrease them.

Grace, a forty-year-old woman labeled with mild mental retardation, has worked in a day program doing packaging and sorting tasks since she graduated from high school. She began refusing to work and started displaying aggressive behaviors toward a younger woman who sat near her workstation. Grace's parents, afraid that their daughter's placement would be jeopardized if the behavior continued, agreed to the services of a behavior specialist.

In the behavior intervention plan that was developed, Grace's parents would be called if there was an aggression "or the threat of an aggression," and they would come to the program and pick her up. At home, her parents were to restrict her from a favored activity that evening as a punishment. Clearly, the behavior specialist's filter for Grace was a behavioral one with a heavy emphasis on consequences. Such "slash and burn" behavior plans are too common, and have been about as helpful to behavioral ecology as slash and burn land use has been to the physical environment. The first step the behaviorist took was to control and punish instead of doing a functional assessment. No one talked to Grace or even did a cursory review of how the environment might have contributed to the behavior.

I encourage a planning process that places the person being served at its heart. "Person-centered planning," "Essential Lifestyles Planning," and "Personal Futures Planning" all focus on what the person needs rather than what the system needs.

When you're using this perceptual filter, you don't talk about placing the person in a group home with people they don't know, or in a day program making widgets, or on goals that have no meaning to them.

Instead, planning starts and ends with the person being served. This puts great strains on the service system because it is individualistic. That is exactly how it should be.

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A Recovering Behaviorist

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If they had looked at Grace through a different perceptual filter, different questions would have come to mind other than, "how can we stop her aggressive behaviors?" Questions such as, "Why would Grace begin such dramatic behaviors after eighteen years without a problem? Why did Grace single out one specific person? What does Grace have to say about this? And what is Grace gaining by doing this, what's the reinforcement in it?"

These are just a few of the hundreds of questions that should be a part of a useful functional assessment. I see the process as similar to putting together a 2,000-piece puzzle that has no borders and is missing some key pieces. I look for subtle coloration as well as distinctive prominences in the answers, and also what's not there that should be. I keep trying to build up clumps of success and understanding, knowing there is a picture of the behavior in there somewhere. I just have to find it.

There are a lot of people who don't see the value in the time it takes to do this. I strongly feel that if we presume to disrupt a person's life like happened in this situation with Grace, there is no issue too trivial and no question too meaningless for us to explore. Even though it can get frustrating and the puzzle parts aren't fitting, or every piece starts to look the same, we have to keep looking. We cannot make the pieces fit through force or begin guessing what we think the picture looks like or, even worse, give up putting the puzzle together.

When we did spend the time to do a functional assessment with Grace, her family and the program staff, we found out that she was bored with the work she had been doing for the last eighteen years, that she disliked younger "kids" coming into the workshop and doing the same job she was doing, and that the younger woman had been teasing her during breaks and lunch. The family wished their daughter could have been challenged more at work, but thought the professionals knew better. When the restrictive program was proposed they were horrified that, if they didn't go along, their daughter would be out of a job.

In the end, Grace did not need a behavior plan. But how had things gone so far? The "noncompliance" and "aggression" turned out to be messages that we weren't tuned in to. Grace's parents trusted that the staff was acting in their daughter's best interest. The staff abandoned their knowledge of Grace and their long-term relationships with her in favor of the "science" of behavioral treatment. The behaviorist focused solely on the target behavior data and how to reduce it. Reinforcement was totally left out of the plan. Knowledge of Grace and the uniqueness she brought to the situation was not even considered.

> Since I am a recovering behaviorist, I continue to ask for data to be collected, and I use some of the behavioral jargon like "reinforcer," "redirection," and "antecedents." But I don't use them in the same way as I did before. My behavior support plans are aimed at building, strengthening, teaching, and interacting rather than restricting, controlling, and punishing.

Person-centered planning was begun and Grace asked for, and received, a promotion to the customer-service section of the day program where she folded clothes and waited on people. Grace and her parents also started going to counseling to begin discussing other goals and to explore what they had to do to begin placement for Grace in a group home. This scenario happens hundreds, perhaps thousands of times every day in group homes, day programs and in families. The addiction to consequence-based, punishment-oriented behavioral treatment in the developmental disabilities service system is potent and has a lot to say about our system's need for control and power over the very people we are supposed to be serving.

To combat this addiction I encourage a planning process that places the person being served at its heart. "Person-centered planning," Essential Lifestyles planning," and "Personal Futures planning" all focus on what the person needs rather than what the system needs. When you're using this perceptual filter you don't talk about placing the person in a group home with people they don't know or in a day program making widgets or on goals that have no meaning to them. Instead, planning starts and ends with the person being served, the consumer. This puts great strains on the service system because it is individualistic. That is exactly how it should be.

Terrence was a mess. He had moved just one month ago from his family home of thirty-five years into a beautiful, brand-new group home and a new day program run by a well-respected provider. Marisa, his mother, had been extremely reluctant to agree to the placement but after many years of Terrence physically abusing her, and her husband and family doctor advocating for it, she agreed.

It didn't take long before things began to unravel. Terrance was placed in a group home with four other men and, all of a sudden, he was faced with adjusting to them as well as the two staff on duty. He had been used to free reign at home but now found that there were rules about using the refrigerator, drinking the juice and soda, how long he could spend in the bathroom and a host of other things.

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A Recovering Behaviorist

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He had to get up early, take his shower the night before, do his laundry on Tuesday and Saturday and...

Terrence's behaviors became unpredictable. Sometimes he would yell and curse, sometimes he would barricade himself in his room, and sometimes he walked out of the house without permission. On several occasions he smeared feces on the bathroom walls and mirrors. At the same time he was also having problems at the new day program where he did maintenance and cleaning. Although he had been successful in his training for this job, now he was spending long periods of time in the men's room, picking food out of the cafeteria trashcans, and responding angrily to redirections by his supervisors. His mother was frantic. She felt that the group home staff disliked her and were treating her son disrespectfully and that the day program staff were lying; her son would never eat out of a trashcan! Her response was to take him home as much as she could and spend long hours at the group home making sure staff were treating him properly.

I received a request from the provider asking for a plan to get Terrence's behaviors under control. I quickly met with the mother (the father did not want to be involved), the group home staff and managers, the day program staff and managers, and Terrence. Reviewing the information I had collected through my positive approaches and systems filters, I knew this wouldn't be resolved by writing a typical behavior plan for Terrence. Several pieces of information were evident:

- Terrence was going through life changes that would be difficult for almost anyone to navigate without symptoms of stress.

- The people in Terrence's life were making decisions for him without integrating them into a unified plan. Terrence was caught in the crossfire.

- Staff were angry at Terrence's mother because of her overinvolvement at the workshop and group home (which they interpreted as lack of trust) and because she obviously hadn't raised him correctly (or he wouldn't be doing all of these terrible things).

- Terrence's mother was angry with staff because she felt ignored and devalued by them, and believed that they had lied to her about how wonderful the group home would be.

- There needed to be some period of transition, adjustment and accommodation for EVERYONE, not just Terrence. Expectations were exceedingly high that there would be no problems and this was unrealistic.

My interventions, which are still in process, are aimed at bringing everyone together to refocus on Terrence as the reason we have our jobs. His needs, and his success, are what we are all working for. I asked the team to talk about difficult transitions in their own lives and what would have helped them move through it better, then shifted the conversation back to Terrence to help them understand what he might be going through. The consensus so far has been, "back off!" To ask instead of tell, request instead of demand, and find ways to praise instead of criticize are all ideas the group came up with to support Terrence.

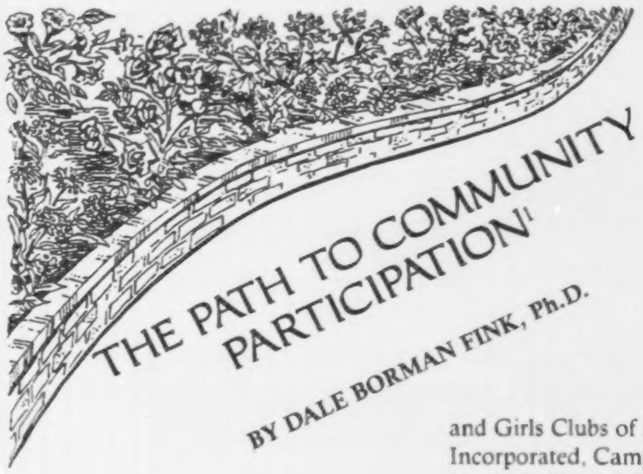
My meetings with staff have emphasized that, in order to help Terrence adjust, they need to spend some time getting to know him and for him to get to know them. They should include him in planning what will happen around the house so that he has input and commitment and will be more likely to be cooperative. Learning about him will show his mother that he is with people who like him and she'll begin to trust staff more. I asked them to think about what it must be like to present your child to anonymous people and have them tell you that you did a lousy job raising him. I suggested including her in activities in the house instead of being hostile and argumentative.

At the day program I worked with staff to build some flexibility into the program by allowing Terrence to come into a more familiar part of the program if he felt the need. Because he was having problems with less supervision than he had been used to and was undergoing a lot of stress in his life, they agreed. We also found a way to have his supervisor give him more targeted one-to-one attention on a regular basis. This also made the mother feel that the day program staff were trying harder, decreasing her anxiety.

I requested of everyone that they consider what we had learned in our meetings and to allow six months for all of the changes and the transition to take hold. During that six months they would see some of the behaviors disappear, some would become less intense, some would stabilize, and some behaviors they would come to accept just because they would know Terrence better.

Since I am still a recovering behaviorist I continue to ask for data to be collected and I use some of the behavioral jargon like "reinforcer" and "redirection" and "antecedents" but I don't use them in the same way I did before. My behavior support plans are aimed at building, strengthening, teaching, and interacting rather than restricting and controlling and punishing. Thank you, Herb, wherever you are.

Jim McFalls is a licensed psychologist and the Director of Adult Services at Ken-Crest Services in Plymouth Meeting, PA. He is a member and past co-chair of TASH's Positive Approaches Committee. Dr. McFalls may be contacted at (610) 825-9360 or by e-mail at JMCFA10439@aol.com



THE PATH TO COMMUNITY PARTICIPATION[1]

BY DALE BORMAN FINK, Ph.D.

"*When I was in Girl Scouts, there were no kids like Erica. And I just didn't know if she could be part of it.*" It was 9:30 in the morning. Katrina, nine-year-old Erica's mother, had put her on the school bus, taken her three-year-old to the church-operated preschool, and fed her one-year-old and put him back down for a nap. I was sitting in Katrina's living room, having contacted her in connection with my research on the participation of children with disabilities in out-of-school activities such as scouting, team sports, 4-H clubs, and recreation centers. I knew from a prior telephone call that Erica did not participate in any of these activities. I wanted to learn more about her situation, to identify the barriers that keep some parents from involving their children labeled with moderate to severe disabilities in activities that are standard fare for many children without disabilities in their neighborhoods.

Youth Programs—the Big Picture

The 15 largest national youth development agencies -- among which are YMCA, YWCA, Boy Scouts of America, Girl Scouts of the USA, Boys and Girls Clubs of America, Girls Incorporated, Camp Fire, and 4-H -- touch the lives of 30 million young people per year (National Collaboration for Youth, 1990). These organizations offer arenas where children and adolescents with disabilities might find avenues for friendship, the development of skills, self-expression, and having fun in a group setting. Since the 1970s, these organizations have revised their guidelines to endorse the concept of inclusion—in contrast to the separate programming and "handicapped units" that most of them encouraged in earlier times. A publication such as Focus on Ability/Serving Girls with Special Needs (Carroll, 1990, Girl Scouts of the USA) illustrates this evolution. But the promulgation of new guidelines and the development of informational resources at the national level in no way assures that inclusive practices take root at the local level where actual programs and services are delivered.

Community Case Study

In selecting a community in which to investigate the out-of-school experiences of children with disabilities, I searched for one that wasn't a college or university town, that didn't have a therapeutic recreation department, and that was not particularly affluent. When children with disabilities and their families had the same choices as everyone else and when resources and specialized expertise were in short supply, would they find the doors to community participation open? And if they found open doors and pushed through them, what opportunities and challenges would they encounter?

The community I chose was a village of 14,000 located in a mostly rural Midwestern county. That is where I met Katrina and that is the context in which I was invited into her home.
I learned that Katrina and her husband had first gotten the diagnosis of cerebral palsy when Erica was six months old. Soon after, doctors found evidence of heart problems, leading to heart surgery on her first birthday. The heart problems were corrected, but the cerebral palsy led to motor problems and severe delays in speech and communication.

Erica speaks maybe 10 words. Her family has tried to teach her sign language. She can do basic signs like "eat," "more," "baby," "drink", "hungry," "please." For "bathroom," Erica grabs herself. It is difficult for her to get her fingers in the correct position to sign the word "bathroom."

Katrina had been in high school when she got pregnant. Now she was a registered nurse, having gone back to school when she was nineteen. What motivated her to get the degree? "*To tell you the truth, I wanted to know what they were saying about my child...the nurses and the physician would always be yapping back and forth.*"

Fears About Community Participation

Currently Erica was attending a self-contained special education classroom in the local public schools. Besides attending school, she joined the family on outings to the municipal swimming pool and played with her siblings and the next-door neighbors' children. She was not having any peer-oriented, group experiences common to other kids her age during the out-of-school hours. When the school sent home information inviting parents to sign up their daughters for Girl Scouts, Katrina gave it some thought and even wrote a note about it

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[1] *Portions of this article were adapted from Making a Place for Kids with Disabilities (Fink, 2000). Names in the book and in this article have been fictionalized to protect anonymity.*

THE PATH TO COMMUNITY PARTICIPATION

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to the paraprofessional that worked with Erica during the school day. But that's as far as she got. Katrina acknowledged that the thought of putting Erica into a Girl Scout troop led to a host of other questions that she had not yet resolved for herself.

"I don't want someone to make fun of her....My husband has a 10-year-old brother; he's not around much but when he is around her, he will make fun of her. She flaps her arms at times, and he'll flap his arms."

"Erica loves to do things away from us, not just with the three kids and us. I know it would be good for her to be with other kids...but you hear so much about camp counselors abusing children. I don't know if I could control myself if something like that happened. My husband says, 'think about when we get older, we're not going to be with her everywhere she goes.' But I can't let myself think about that."

"When my husband was younger, he was kind of an overseer for a group home, for kids from about age 18 to 25. And...they had people coming in and talking about sex. I mean actually telling them how to do it....I just don't see her as cognitively being able to deal with that kind of information....There was one girl in this group home that got pregnant. And she wanted to get pregnant. I just don't know if I can ever accept that!"

How many moms or dads of nine-year-old girls without disabilities bring such a complex web of concerns to a decision about whether to sign up a child for a scout troop? For Katrina, thinking about her daughter's participation in a community activity with typically developing peers was an exercise charged with emotion. It raised concerns about how other children would respond and fears about adult leaders who might be insensitive or even abusive. These worries in turn were related to Katrina's anxieties about what level of functioning, competence, and independence her daughter would attain far into the future.

It was not my role to help Katrina resolve these larger issues. But because I had already met with leaders of the local Girl Scouts, I was able to reassure her on one point. "If you sign Erica up for Girl Scouts," I told her, "she does not have to attend without you. All parents are welcome to attend the troop meetings." A few months later and as a direct outgrowth of our discussion, Katrina enrolled Erica in one of the local Brownie troops.

ERICA JOINS A BROWNIE TROOP

Although Erica was old enough to be in a Junior Girl Scout troop, Katrina decided in consultation with the troop leader and a regional volunteer "troop consultant" to put her in a Brownie troop. They all agreed she would have a better chance of meaningful participation with girls who were in first and second grade than with typical peers of her chronological age. The troop Erica joined had as its leader Francine, a special education teacher and mother of one of the troop members. Weekly meetings were held in the cavernous Fellowship Hall of a local church.

Erica's demeanor at the meetings was friendly, open, and smiling. She had curly, close cropped, blondish hair and rosy cheeks. Her weight was in proportion to her height; she looked about the right size among a group of mostly seven year olds.

Katrina had described her daughter to me as having a stiff "Russian soldier" walk. This was noticeable, but what accentuated her developmental differences was the way she interacted with people. She used physical touch as her way of getting and keeping the attention of a peer or adult. I saw her try different approaches, from full frontal hugging, to taking a hair band off another girl's head and putting it on her own, to strongly taking hold of both hands of another person (adult or child), and pulling on them.

THE PARENT'S CHANGING ROLE

When Katrina first began bringing Erica to Brownies, she remained with the group the entire time, sometimes sitting right with Erica, sometimes watching from a nearby table. Just as she had told me in that first interview, she wanted to make sure she was comfortable with the leaders, and confident the other girls would be accepting toward her daughter. During the color guard ceremony, which included the Girl Scout Promise and Pledge of Allegiance, Katrina helped her daughter stand in the right place, but didn't worry about the fact that Erica held up the wrong hand. During a circle game, Katrina joined in, and tried (without much success) to get Erica to run around the circle on her own, when she was tagged. During a "secret code" activity that Erica did not seem to comprehend, Katrina helped her use her pencil to draw some letters and pictures.

After the first few meetings, Katrina began leaving for part of the time and returning before the meeting ended. One week the troop members were invited to accompany their leaders to a theatrical production on a Friday evening at a high school in a nearby city For the first time, Katrina let Erica participate without her. It went fine. From that point on, Katrina began walking her daughter into the foyer outside the Fellowship Hall and saying good-bye like the other parents.

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THE PATH TO COMMUNITY PARTICIPATION

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MOMENTS OF GENUINE INCLUSION

Still, Erica's participation was not comparable to that of her peers. Much of the time, she took little notice of the matters on which their attention was focused. One day I was part of a small group whose task was to brainstorm ideas for food for a Valentine party. As the other Brownies fed ideas to one girl who was writing all the suggestions on a list, Erica's eyes and attention wandered to the far corners of the room. Just when she appeared to have completely tuned out the activity, one of the other girls called out a suggestion of "popcorn." Suddenly Erica's eyes were riveted and her body language registered enthusiastic engagement. Francine, who had been watching from a distance, walked over and asked her, "Erica, you want to have popcorn at the party? Everybody, raise your hand if you want popcorn." The other girls raised their hands, and so did Erica. In that moment, she was at one with the thoughts and emotions of her peers.

When the Valentine Party took place two weeks later, one of my jobs was to blow up balloons. Erica's attention was quickly drawn to the red and white balloons, but she also acted terrified of them, walking far away and standing at the other end of the long Fellowship Hall. But in a few minutes, she recovered her courage, came closer, and soon enjoyed bouncing a balloon back and forth with me and knocking it up high in the air. The first time one smacked her in the face, she acted frightened and verged on tears. But quickly she grasped that it did not hurt and could be part of the fun. Other girls began helping to blow up balloons and bounce them around the room and to one another. They were following the lead that Erica and I had established with our balloon play.

IT TAKES A BOOK TO DESCRIBE A VILLAGE

This article offers a brief glimpse into the early months of one child's inclusive experiences as well as depicting the path that brought her there. Over the course of a year, I interviewed the families of 19 children with disabilities in the case study community and followed a dozen of the youngsters into their community activities. I also interviewed the volunteers and paid leaders associated with each program. The complete findings of the study are available as a book (Fink, 2000).

What compelled me to this investigation was the desire to get beyond "inclusion in the community" as a philosophy and examine what that participation looks like in daily practice. I wanted to provide a series of snapshots that could become jumping-off points for future discussion as well as for further research.

One lesson from this case study is that simply initiating a conversation can sometimes stimulate the process of change. As described earlier, I was anticipating writing about Erica as a child who was not taking part in any inclusive out-of-school programs. The interview itself changed that. Katrina learned from me that parents were always welcome at Girl Scout meetings. This reassured her and led her eventually to enroll her daughter in her first community activity with typical peers. This example underscores what little effort is sometimes required to knock down a barrier to community participation. It is also a wonderful reminder that in qualitative research, the process of investigation sometimes influences the people and practices we are studying. I look forward to hearing from readers who are starting conversations of their own or taking other actions to influence the people and practices in their own communities and organizations toward greater and more successful community participation of youth with disabilities.

Dale Borman Fink is an independent scholar, conference speaker and author living in Williamstown, MA. At times his sister, Laurel, who has Down Syndrome, has joined him at the podium.

Dr. Fink's publications include School-Age Children with Special Needs: What Do They Do When School Is Out?, Toward New Strategies for Inclusion; and Making a Place for Kids with Disabilities. Questions or comments about this article my be sent to the author via e-mail at <finddale@sover.net>

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Families planning together

BY MICHAEL W. SMULL, MARY LOU BOURNE, AMANDA GEORGE, AND SHELLEY DUMAS

Karrie is a young woman who is described by those who like and admire her as a helpful, hard worker, with great stamina. Not too long ago she was also seen (by the staff of the agency that supported her during the day) as someone who was difficult to employ and who needed a behavior program.

Karrie's mother, Bonnie, is like many parents we have met. She didn't agree with the agency staff. The Karrie that she knows and loves is someone that needs to have people who support her know how to approach her. Any job that she has must take into account who Karrie is and what she likes and dislikes.

Through a process called "Families Planning Together," Bonnie was able to gather what she and others who love Karrie have learned about Karrie over the years. Bonnie was not only able to develop a detailed plan that describes Karrie but also a one-page description of what should be present or absent in any job that Karrie does. Bonnie says, *"This plan gives Karrie authority; it changes the way people are required to do things with Karrie. We have found that some providers are able and willing to do things the way Karrie needs, others still just want Karrie to conform to the way they do things."*

People labeled with severe disabilities, who are unable to speak for themselves, need a voice. They need to be able to describe what is important to them. For those individuals, their families are often the best choice. But the families need to:

- Have structured ways to gather and organize what they know

- Be able to separate what is **important to** their family member from what they see as being **important for** their family member.

- Be able to take what they have learned and have a structured way to write it up so that it communicates powerfully to others.

- Have easy ways to continue to learn and reflect that learning in what is written

- Know how to use the resulting plans to accomplish their goals

Meeting the needs with Families Planning Together

In order to help families in meeting these needs, our group has developed:

- A "Families Planning Together" manual complete with sample plans that are posted on the web <www.allenshea.com> that can be down-loaded for free

- Seminars (and a manual describing the seminar) where we help families begin the development of plans by "walking through" the manual

- A process to help interested family members to become "family mentors." Family mentors are people who have completed plans with their family member and have been supported in learning how to help other families develop plans.

Some of what is needed is still under development. We know that many families are beyond the physical reach of the seminars that we have started. We have a few family mentors in Pennsylvania, Missouri, and Texas; we will need many more. We especially need to develop ways to help families from a distance, using the World Wide Web, and other distance learning techniques. However, what we have been able to accomplish is working. What follows will tell you more about those aspects.

Seminars introducing people to the process and beginning to develop a plan

In Families Planning Together (FPT), families learn a structured way of gathering and organizing what the person they are planning with has told them (and others). They are shown a step-by-step process that will enable them to develop an "essential lifestyle plan" with their family member. After attending either a one-day session or three evening sessions (6 hours total), families know how to use the Families Planning Together manual to develop a plan with their family member. They have made a good start in developing a plan and know how to get on-going assistance. The seminars are currently

Kathy heard about the Families Planning Together seminar while talking with another parent who had already developed a plan with her son that was being used at school. When Kathy read the plan, she was amazed at all of the information it contained and how clearly it described her friend's little boy. "I wanted something like that for my daughter, so I signed up for the seminar." After attending, Kathy had learned enough to start writing a draft of her daughter's plan. She now gives Justine's plan to Justine's teachers and other family members like Justine's grandmother. She says that the plan has helped others to better understand and support Justine.

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being led by people trained as trainers in essential lifestyle planning but will be led by family mentors as they get the experience needed to feel comfortable and competent.

Using the workbook in the seminar, families are encouraged to think about planning as occurring in four stages:

1. Think before you plan
2. Gather information
3. Develop a first plan
4. Ongoing learning

Think before you plan

Families are asked what they want the plan to accomplish, what they want to learn, who needs to be involved and above all how to make sure the process is respectful to their son or daughter. Families consider these questions in relationship to what the actual purpose of the plan will be. Bonnie stresses that she developed a plan with Karrie because (in part), *"All of this information was inside of the people who love and care about Karrie. No one else knew this - we needed to get it written down."* Some of the most common reasons families have for developing plans are:

- to have a place where it is all written down -- the "just in case" plan

- to help others get to know the person better. It t is used by the people who provide support.

- to help with a life transition -- from school to work, or from the family home to a home of one's own.

- to figure out what is important to the person and what types of support make sense, then use the information to create supports and recruit providers of services.

Gathering information

After thinking through what they hope to accomplish, families start stage two, information gathering. The first person to gather information from is their family member. Families learn how to ask questions without built in answers and questions that don't lead the person. The second part of information gathering is "learning from others." Families learn not only who to talk to but who to listen to. They listen to (and record) the answers to questions like what do you like the most\admire the most about their family member. Some of the people families talk to include: family members themselves, extended family and friends, others who know and care about the person, and people who have been paid to support the person. People have collected information in many ways, including phone conversations, e-mail messages, face-to-face interviews, and having information-gathering parties.

> *When Bonnie started gathering information for Karrie's plan, she says, "At first I was overwhelmed. How am I ever going to be able to do this? Then I realized, just a little bit at a time."*

Writing a first plan

Although the seminar walks the families through the process, most of the writing is done at home. Families write at their own pace, using all of the source information they have gathered. They organize the information into three primary sections:

1. What do others like and admire about the person
2. What is important to the person
3. What others need to know or do to support the person (which includes what is important for the person such as issues related to health and safety).

In the manual, families are given a blank plan format, which they can use to hand-write their plan. For families that are interested in writing their plan on a computer, a template is provided at the seminar. The template was developed in Microsoft Word, and it provides an easy way to create a plan that can later be updated and changed as needed.

Implementation: using the plan and ongoing learning

When families have developed a plan that is good enough to get things started, it is critical that they continue to work on the plan. Plans that are used must change with the person. As the person changes, as learning occurs, and as people's understanding of the person grows, each plan needs to reflect the new information and any changes to the existing information. The manual describes a number of ways to record new learning and keep the plan up to date.

> *Shelley has updated Katherine's plan over a dozen times in the three years she has been using it. One of the ways that she continues to gather information is to have the communication section of the plan travel with Katherine, in the backpack on her wheelchair. When those who support Katherine see her telling us something new with her behavior, they write it down.*

Family Mentors

A family mentor helps other families develop plans with their family members. They help people learn and understand. They guide, connect and encourage. While they need to be knowledgeable and enthusiastic about developing plans, mentors are not responsible for developing the plan and do not direct its development. Being a mentor requires being comfortable in a role of helping and encouraging rather than doing or directing. A mentor also needs to be comfortable with what they do not know and able to help people

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connect with those who do know. We are finding that it is easier for families to fill this role than it is for professionals.

> *Bonnie found that "writing a plan with the help of other families really improves your confidence. I don't think a lot of families would go through with this if they didn't have other family members encouraging them."*

A family mentor not only helps families develop plans but also helps them in keeping the plans alive. Mentors discuss the ongoing support that the family thinks they may need and how that support can be obtained. Bonnie has decided to continue as the facilitator of Karrie's plan, using it for updates and reviews. For another family it made more sense for a service coordinator to continue updating the plan. The service coordinator was able to use the plan to negotiate with her service provider to decrease the number of days the family member pays for daytime support. This money is then used by the family member to purchase other supports.

Being a family mentor is not for everyone. It not only requires the characteristics listed but it takes time and energy. Those who would like to be mentors first have to work on the plan with their family member long enough for it to be considered a good plan. Then they have the opportunity to spend time learning how to conduct the seminar, how to review the plans the others write, and learn some exercises that can help with things like building connections or finding a new place to live. This learning can be spread out so that it fits with busy schedules but it does take time. While they are learning we encourage them to start mentoring one family at a time and get support while doing it. We are also seeing if mentors can be paid for their time and/or their expenses by the states. Under some Medicaid waivers, paying one family to help another with planning appears possible.

> *Kathy, who is a family mentor in Missouri, says she loves supporting other families to learn about their sons and daughters and then seeing it make a positive impact on their lives. As she has helped families with the planning process, she has seen the "light bulbs" go on for many families that have been struggling to figure out how to better support their children.*

Some mentors just want to help one family at a time while others are interested in working with larger numbers. Some are only interested in helping with the planning and others are interested in helping with implementation and advocacy. Once mentors have demonstrated the basic skills of supporting other families with planning whatever role they want is one that we will support. But this is still new for us and we have a great deal of learning left to do in learning how to recruit and support family mentors.

Missy's sister, Donna, pointed out that from her perspective as a sister and a daughter, it was very helpful "watching my parents go through the details step by step. It was the process that helped them accept the whole idea of Missy living on her own. Having the mentor (available) made us feel very comfortable talking about sensitive and private topics. My parents didn't get that feeling before." Many family members report that when talking about something different from what was already present, conversations with professionals always seemed to focus on the many things that could go wrong, as if nothing could be done to prevent risks. As a result, many families have been reluctant to try anything out of the ordinary. Missy's family, with the support of a mentor found that Families Planning Together "helped us plan for the details that would minimize the risks for Missy. When we knew how to pay attention to the details, we were all much more comfortable with planning around the idea of Missy living in her own place with a friend. Even as quickly as it all occurred, we felt better prepared."

Creating positive pressure for change

We want self-determination to be available for everyone. Making that happen not only requires that people have control over their resources but also knowledge. They need to know whether what is being offered will address what is important to them. They need to know what has been done in other places, not just what is on the local menu. This knowledge creates positive pressure for change. It is another piece of what is required for the system to change. Often, families have great ideas about how supports can be arranged, but the system resists the changes needed to make it happen. By putting these ideas into a plan, families can apply that pressure. Tracy, a service coordinator said, "Families are the best advocates for their family member; staff or professionals may overlook important details in what is important to someone or how best to support someone...families make sure the details are there." Ten families (or self-advocates), armed with the knowledge and confidence that comes from developing their own plans, are more effective than 100 support coordinators in advocating for change.

While we have been describing how families can learn to plan we want to emphasize that the same process works for many self-advocates. Where people can develop their own plans they should be supported in doing so. We are working on making this easier and more available, however, it is beyond the scope of this article. When you listen to the stories that families tell the importance of our current efforts are clear. Their stories are more powerful than anything that we could say. What follows are just a few of the many stories that we have heard.

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Levi and Carol
After developing Levi's plan, Carol says, *"...I always noticed that if I talked or wrote about a problem Levi was having, I found ways to solve the problem without too much help from anyone else. As I was gathering information and writing his plan it helped me focus on what the problem was, what caused it and how to go about making things better for Levi."*

Brittany and Elaine
Elaine developed an Essential Lifestyle Plan with her daughter, Brittany, about three years ago. This year, Brittany started high school and her teacher has been very interested in making sure all students get to know Brittany. Since Brittany doesn't use words to communicate, her teacher uses her plan as a way to help others get to know her. Her teacher has shared Brittany's ELP with Brittany's friends, especially, her likes, dislikes, her dreams and her communication chart. Some really neat things have happened. For instance, one day, Brittany had nine freshman boys lined up along the hall serenading her before lunch. It was all because they found out her favorite groups were N'Sync and Back Street Boys. Brittany's teacher is also helping her do things that are important to her and to realize some of her dreams which are listed in Brittany's plan. For example:

❖ Brittany wanted to join a club and help others. She belongs to the FCLA (Future Consumer Leaders of America) at the school. She pays her dues. This club sponsors the school blood drive.

❖ Brittany wanted to help out with the breakfast bar at school. She is the high school Breakfast Club Hostess in the morning.

❖ She wanted to develop her own line of purses. Brittany created a purse in her Family and Consumer Sciences class.

❖ Brittany wants to be a model. Her teacher is producing a Breakfast Bar commercial and Brittany will star in it. Elaine says, *"Brittany is giving the best smiles in the world these days when she comes home from school."*

Katherine and Shelley
"Although Katherine had a person-centered plan since she was sixteen, it was really a plan that reflected what her dad and I wanted for her, not what she wanted, because, after all, she was a person with "the most significant support needs." She could not tell us what she wanted and we had accepted her fate of having to settle for less than most other people would want and expect in their lives.

Because Katherine, her Dad and I had some experience in planning, she was asked to volunteer to help some professional staff from our local service agency learn a newer way of planning, Essential Lifestyle Planning. Katherine and I went to the training where Katherine was the focus person for development of a plan by a facilitator/trainer.

At the end of the two-day training, Katherine left the building her same self, having had a wonderful time. I left the building with a load of chart papers and a brain transplant. I stared at Katherine for at least two days, and kept apologizing to her for years of not listening to her. Encouraged by my husband to 'get a grip' on myself, I entered all we had learned into an Essential Lifestyle Planning format on my computer, still amazed to see such new truths as 'Katherine is a teacher...a food critic...a Zen master...and, characteristics of people who should support her.'

Having structured this information into a document that could be easily understood by professional staff, Katherine, her dad, and I took it forward to the agency supporting her. And her life changed.

That was 1998. Based on what we learned, and continue to learn, Katherine participates in hiring the people who support her. Her days are spent doing more of the things she enjoys doing as an adult. And one of the most powerful outcomes of listening to her is that we are supporting Katherine to develop her career as a teacher/trainer. She's taught workshops in Texas, Florida, and later this year, in Arkansas. She's taught teachers, support staff, and service coordinators. She's taught them how to listen to behaviors as communication, and she's taught them how to think differently about people they support. She's teaching person-centered thinking. She's changing systems.

Although her trainings allow Katherine to be Katherine, to do the things she likes to do, and to interact with different people at each training site, she is developing new skills. She's learning to press the button on the computer to change the presentation slides. Her co-trainer (whom she helped hire) says, 'When I look at Katherine presenting her communication training, I see a person happy at work.'"

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For more information about the Families Planning Together process, contact Michael Smull at <mwsmull@compuserve.com>; Amanda George at <Agpan@aol.com>; Mary Lou Bourne at <mlbourne@assdcat.com> or Shelley Dumas at <s.dumas@mail.utexas.edu>; or go to www.allenshea.com, click on M. Smull and Friends, and look for the message to families, the Families Planning Together Manual and sample plans.

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The Evolution of an Unlikely Partnership Between Researchers and Culturally Diverse Families: Lessons Learned

BY BETSY SANTELLI, The University of Kansas,
URSULA MARKEY and AGNES JOHNSON, Grassroots Consortium on Disabilities, and
RUD TURNBULL and ANN TURNBULL, The University of Kansas

Historically, partnerships between large, well-established organizations in the dominant culture and smaller, newly developing, community-based efforts on behalf of un/underserved families have been beset with challenges stemming from cultural differences, varying priorities, and a lack of trust (Kritek,1994). Kritek (1994) describes how cultural discrimination results in people attempting to negotiate at an uneven table — one to which un/underserved families and representatives of veteran organizations, such as university-based researchers, come, ostensibly with equal power but actually with highly disparate power. Parent-directors of community-based family support centers operate within the context of un/under-funded community settings and provide support and information to families with multiple challenges. Their efforts often go unnoticed and unrewarded. Researchers often operate within the context of well-funded university settings, and conduct research as one of their many academic requirements and expectations. Universities reward their published research with promotions and tenure. And more often than not, and sometimes with just cause, culturally and linguistically diverse families believe that researchers come to their community, conduct their research, and then leave — all without creating any direct and immediate benefit to the families.

How then does a partnership develop between a national coalition of parent-directed community-based family support and information programs serving culturally and linguistically diverse families who have children with disabilities and a well-funded research and training center? The Grassroots Consortium on Disabilities and the Beach Center on Families and Disability at The University of Kansas were well aware of the potential pitfalls as we embarked on a mission to establish a partnership built on a foundation of an enhanced mutual understanding, trust, respect, and equal participation in all decision making.

THE PARTNERS

The Beach Center on Families and Disability

The Beach Center is a Rehabilitation Research and Training Center (RRTC) that has been funded since 1988 by NIDRR's Rehabilitation Research and Training Center Program All of its research, training, technical assistance, and dissemination activities focus on family and policy issues related to disability, and its major commitment has always been to conduct research and training that will make a significant and sustainable difference in the lives of families who have a member with a disability by influencing individuals with disabilities and their families, service providers, researchers, and policymakers.

The Beach Center does not provide direct service to families on a day in, day out basis but, rather, the Center tries to make a difference in the lives of families by:

This partnership will provide a model for collaboration between sophisticated, highly developed research entities and families all across the nation in the interest of improving the quality of life for all children and adults with disabilities everywhere. The promise is that participatory action research (PAR) teams composed of researchers and culturally and linguistically diverse families will discover a new relationship that broadens the scope of their commitment to research as a means of social change and contributes to a deeper understanding of the critical role research plays in finding practical solutions for families.

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- providing families with research-based information that leads to resources and skills for meeting their needs, and the motivation to use those data, resources, and skills for their benefit

- helping to change policy and practice so that the families' context responds to their needs and efforts

The Grassroots Consortium on Disabilities

The Grassroots Consortium on Disabilities is a national coalition of community-based, parent-directed, family support and information programs serving culturally and linguistically diverse families who have children with disabilities and other special needs and who are living in traditionally underserved communities. These are communities that have become isolated due to racism, discrimination, cultural and language differences, and/or because they are located in distressed urban or remote rural areas.

The services are individualized, flexible, and comprehensive and often include assistance with meeting basic life needs related to poverty along with the disability-related needs. Each program serves and represents traditionally and historically un/underserved individuals with special needs and their families, including families who are African-American, Asian, Hispanic, Native American, and European in their racial or national background, and/or who are migrant workers.

While each of the programs is unique in how it supports families, activities that are common to all of them include outreach, informing parents about the educational and legal rights of their children with disabilities, helping families to meet their basic needs through nonjudgmental, ongoing, one-to-one technical assistance delivered by parents who reside in the home communities, and sponsoring parent leadership and community development.

> If research does not include culturally diverse families, will its results be relevant to culturally diverse families? And if these families are not involved in the research activities, how will the investigators know what questions the families want answered, what products to develop, what training methods to use, and what languages to publish in?

All of the Grassroots Consortium's programs have been developed and administered by culturally diverse parents of children and adults with disabilities who operate their programs on a shoe-string budget and who strive for the greatest possible personalization and responsiveness to underserved minority families. Most of the programs have at most 2 or 3 part-time staff, and many of the programs operate out of the parent director's home with access to a single computer and one telephone/fax line. Yet, despite few tangible resources, the 14 programs have, over the past six years alone, served over 150,000 families in over 50 communities; they have received Presidential, other national, and state-regional awards; their members serve on a host of state-regional disability policy-making entities; and the families served by the Consortium's programs report high levels of satisfaction with the services.

The Beach Center on Families and Disability and the Grassroots Consortium on Disabilities - unlikely research partners? Yes. Successful research partners? Yes. Still learning about each other and our research partnership and equally committed to its continuing evolution? Most definitely! Why? Because without the personal and professional wisdom of members of the Grassroots Consortium on Disabilities on meeting the needs of un/underserved families affected by disability issues, the research, training, and dissemination activities conducted by the Beach Center will face unnecessary difficulties in being relevant and appropriate for families represented by the Grassroots Consortium on Disabilities. And, without the professional expertise in research methodology and the national visibility of the Beach Center, the best practices for meeting the needs of un/underserved families currently being implemented by the Grassroots Consortium on Disabilities may not be awarded the credibility among the research and service delivery communities that these practices deserve. Our partnership enhances the capacity of each of our organizations to fulfill our mutual mission — to make a positive difference in the lives of individuals with disabilities and their families. Our shared mission forms the foundation of our partnership.

Our shared belief in participatory action research (PAR) and our commitment to be fully participatory as a partnership is the indispensable means through which we have been working and will continue to work. Our use of PAR has helped to ensure that

(a) the Grassroots Consortium on Disabilities programs have had opportunities to expand their skills in the use of research and its results to directly benefit the families served; and

(b) the Beach Center has increased its multicultural competence and is conducting research that is more relevant, meaningful, and immediately beneficial to underserved families.

EVOLUTION OF THE PARTNERSHIP

Initial Outreach

The Beach Center staff member who serves as its liaison to parent groups nationally has for the last 12 years

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regularly attended national conferences of parent organizations such as the Parent Training and Information Centers and Parent-to-Parent. Generally at each of these national conferences, there is at least one session on multicultural issues. Attending these sessions afforded the Beach Center liaison with opportunities to learn more about the needs of and best practices for serving culturally and linguistically diverse families. A consistent Beach Center presence at these sessions also increased our own visibility with the parent leaders directing parent support programs serving traditionally underserved families. When the program directors of multicultural parent support and information programs were able to have, for the first time, a retreat of their own, the Beach Center liaison offered to attend to (a) learn more about these multicultural parent support and information programs, their families, their best practices, and their issues and challenges; (b) continue to build relationships with the directors of these programs; and (c) to enhance their awareness of the resources of the Beach Center — those developed out of our research and those we have because we are a national resource with national visibility and many national connections. The offer was accepted.

Parent-directors of more than a dozen multicultural family support programs attended the retreat. They came eager to share resources and mutual support. The Beach Center liaison had an opportunity to learn about the many strengths of these programs and their parent leaders. The parent-directors however, were cautious about the Beach Center's presence, and asked challenging questions and shared candid observations about the activities of federally sponsored research centers (including, the Beach Center).

- If research does not include culturally diverse families, will its results be relevant to culturally diverse families?
- Since most of the families being served by their programs are dealing with incredible poverty, health, language, and cultural issues, will a center's products be useful?
- If researchers do not involve families in their activities, will the investigators know what questions the families want answered, what products to develop, what training methods to use, and what languages to publish in?

The Beach Center response was to really listen, hear them out, recognize our own shortcomings, and pledge our interest in strengthening our own efforts and supporting theirs.

Later in the meeting, the parent-directors decided to establish themselves as the Grassroots Consortium on Disabilities — believing that as a national coalition they could be more effective than as simply directors of individual community-based programs. A group discussion about ways to enhance their fundraising and organizational capacity generated many ideas. As the ideas surfaced, the parent-directors had an opportunity to hear how the Beach Center might be able to help their ideas become reality. They began to understand some of the relevant strengths of the Beach Center.

These frank discussions were the first real stepping stones of our evolving partnership. The level of candor that framed our discussions was possible because of the ground work laid during the earlier phase of the partnership. A sufficient comfort level allowed us to go beyond the usual polite discussions that are often a part of early relationships. The parent leaders felt comfortable enough to put their cards on the table and the Beach Center liaison felt comfortable enough to understand that not all of their anger was directed at the Beach Center and to accept their honest critique.

Expanding the Partnership

Over the next year, the Beach Center continued to connect in a variety of ways with the members of the Grassroots Consortium on Disabilities to demonstrate our commitment. Through a series of quarterly mailings to each Grassroots program, we shared additional information and resources. A series of conference calls (hosted by the Beach Center) and visits by Grassroots program directors to the Beach Center (paid for by the Beach Center), allowed us to identify the challenges and possible benefits of working together. We agreed to give it a try.

Our First Joint Activity

Since the Grassroots Consortium on Disabilities was working hard to establish itself as a national presence, its program directors were particularly interested in (a) documentation of Grassroots success stories, (b) validation of Grassroots strategies, and (c) funding

Figure 1: Partnership Strengths

Beach Center Strengths	Grassroots Consortium on Disability Strengths
Knowledge about research	Knowledge about underserved families
National visibility/connections	Connections to underserved families
Rich in majority culture resources – financial, organizational, professional training	Rich in minority culture resources –cultural awareness, sensitivity, credibility with families

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Figure 2 Challenges and Benefits of the Partnership

Challenges	Benefits
Establishing trust among partners with little experience with each other	Relevant research for all families
Framing partnership to meet the needs of two very different organizations that share a common mission, but have significantly differing levels of resources available to them to carry out their activities	Methodologies are scientifically rigorous and comfortable for families
Time to get to know one another; to allow for differing paces and competing demands of the partners; for mutual education that allows for informed and democratic decision-making	Increases researchers' access to families as participants and participatory action research (PAR) team members
Funding to equalize disparate resources and to support ongoing communication among all partners	Increases families' access to research-based results and products that reach families in more meaningful ways
Designing fundable, rigorous, immediately beneficial research	Mutual learning opportunities
Minimal support for the partnership from respective systems	Enhances capacity of both partners to accomplish their similar missions

to support its efforts. The Beach Center shared its interest in enhancing its own cultural competence and for involving culturally and linguistically diverse families in all phases of its research. Given these identified needs, we agreed, as a first project, to partner on the submission of a grant to NIDRR in the area of dissemination of research to underserved families.

The process of writing this grant involved one 3-day face-to-face meeting at the Beach Center with the Beach Center funding the travel expenses of the parent-leaders; multiple conference calls, and shared responsibilities for preparation of the grant itself. While the grant was not funded, through this process we learned a great deal about each other and our working environments, and how important a shared, intense, time-sensitive activity is to strengthening a partnership. We were living our partnership and no longer just talking about it. We also learned that there were some who had reservations about our partnership — some from within university settings who feared a potential loss of scientific rigor, and some from within culturally diverse communities who feared a loss of autonomy for the Grassroots Consortium on Disabilities. Despite these reservations, our commitment to maintain and expand our partnership grew.

Ongoing Partnership Activities

Over the last five years, we have engaged in many more joint activities - activities that have, in turn, been of primary benefit to Grassroots or to the Beach Center, but all of which have had common and mutual benefits. With each shared activity, our partnership is strengthened, and our resolve to continue to work as partners is deepened.

LESSONS LEARNED AND SUGGESTED BEST PRACTICES

1. We created opportunities for sharing family and professional stories and getting to know one another as people.

2. The mailings that went out from the Beach Center after the retreat helped to maintain the progress made at the initial retreat. With each subsequent mailing, members of the Grassroots Consortium on Disabilities had more reason to believe that the Beach Center had not just dropped in "for a touch of color."

3. Planning specific activities to undertake together brought to the surface issues that might otherwise have remained submerged. These issues could then be dealt with as they arose. The early grantwriting adventure helped us to understand more clearly our respective contexts, as well as our own differing paces for addressing issues and taking action.

4. We committed ourselves to open an honest dialogue about our PAR process and its promises and pitfalls.

5. We recognized and affirmed the strengths and perspectives that each team member brings to the table, and developed roles that take full advantage of these diverse contributions.

6. We worked to understand the contexts and realities of each of the partners, and recognize that our progress as a team may be slower as a result of these realities.

7. We allowed each partner time to involve all of its members fully in discussions about our partnership so that decisions were made with full participation and information.

8. We recognized that not all activities can equally benefit both partners all the time.

9. We identified a leadership team for each organization and a single point of contact for each organization. The leadership teams hold conference calls and/or face-to-face meetings to revisit our shared vision, define critical issues, determine priorities, and outline action plans. Each leadership team shares information about these discussions with the wider membership of its organization and solicits input. Input from the

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The Evolution of An Unlikely Partnership: Lessons Learned

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membership may mean that additional conversations are needed between the leadership teams. As decisions are made, each leadership team is responsible for follow-up activities.

10. Having developed a basis for trust, a belief in good intentions, and a commitment to the partnership, we weathered and learned from the "Ooops" factors. We identified and corrected mistakes that were made of inexperience or misperceptions.

11. By acknowledging that our efforts to break new ground came with possible risks for each partner as well, we strengthened out relationship and underscored our commitments to each other.

12 We continually nurtured and refined our partnerships and the relationships within them. The process of partnering evolves and changes with each adventure and requires time to assure the quality of the partnership as well as its joint activities.

SUMMARY

We end with two quotes. The first is from an earlier article co-authored by members of our partnership. *"This partnership will provide a model for collaboration between sophisticated, highly developed research entities and families all across this nation in the interest of improving the quality of life for all children and adults with disabilities everywhere. The promise is that PAR teams composed of researchers and culturally and linguistically diverse families will discover a new relationship that broadens the scope of their commitment to research as a means of social change and contributes to a deeper understanding of the critical role research plays in finding practical solutions for families.* (Markey, Santelli & Turnbull, 1998).

The second quote is from Martin Luther King, Jr.: "*Cowardice asks the question, is it safe? Expedience asks the question, is it politic? But conscience asks the question, is it right? And there comes a time when one must take a position that is neither safe, nor politic, nor popular, but he and she must make it because their conscience tells them it is right.*" The members of our partnership made such a decision when we committed ourselves to this collaboration. It is the right thing to do for underserved families and for researchers.

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Questions or comments about the Beach Center-Grassroots Consortium collaborative partnership may be addressed to Betsy Santelli, The Beach Center, by phone (763-525-0509) or e-mail <Betsy@dole.lsi.ukans.edu> or Ursula Markey, Grassroots Consortium on Disabilities. Ms. Markey's e-mail address is: <DMarkey404@aol.com>

Ticket to Work and Work Incentives Improvement Act: Concerns and Recommendations

Continued from page 4

- Base all outcome and milestone payments solely on the level of real income earned by an individual.

The role of state vocational rehabilitation agencies and the relationship between VR agencies and other providers is not clearly defined in the proposed regulations.

As proposed, there is significant concern that state vocational rehabilitation agencies will dominate the system. SSI and SSDI recipients are "presumptively eligible" for VR services. If an individual's Ticket is assigned to VR when they are accepted for VR services and develop an Individual Plan for Employment, that individual is effectively denied the ability to use the Ticket at a later time, without providing access to services that they were not already entitled to.

Recommendations:

- Clarify the assignment of tickets to state VR agencies.
- Provide individuals with clear authority to access VR services that they are eligible for without assigning their ticket.

The proposed regulations do not provide incentives for reducing cash benefits for individuals who are not able or unwilling to work on a full time basis.

The Ticket to Work legislation clearly establishes reduction of cash payments as a goal. As proposed, the regulations only provide payment to Employment Networks for individuals who are receiving no cash payment. Under the SSI program, with gradual reduction of cash

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The following principles were developed by a work group of cross-disability leaders that was formed following the National Summit on Self-Determination and Consumer-Direction and Control, held in October, 1999. The work group developed draft principles which were circulated for comment to over 10,000 cross-disabilty individual and family leaders. They were revised based on the feedback received and stand as the first set of cross-disability principles developed for advancing self-determination and individual and family partnerships for self-determination.

-Submitted by Judi Chamberlain (Co-Facilitator), SunnyChoi, Patti Hackett, Simi Litviak, Trinia Osher, Laurie Powers, Teresa Rankin, Sue Swenson, and Ann Turnbull, (Co-Facilitator)

DRAFT PRINCIPLES FOR INDIVIDUAL AND FAMILY SELF-DETERMINATION PARTNERSHIPS

Families are defined as two or more people who regard themselves as a family and carryout the functions that families typically perform. They may or may not be related by blood or marriage; they may or may not live together; and they are almost always influenced by their own definition of family.

The following principles relate to the definition and expression of self-determination within families and the development of partnerships among family and individual leaders to advance self-determination.

1. Everyone should have the choice to be part of some type of family. Relying on other people can be a good thing so long as the parties agree to it.

2. Families usually hold generational expectations for the expression of self-determination by all family members, including grandparents, parents and children.

3. How families and individuals view self-determination and work together to express it will be based on their culture and values. Self-determination should be defined, expressed and respected within the culture of individuals and families.

4. Individuals with disabilities and other family members may vary in their commitment to, and expression of, the principles of self-determination due to factors such as nature and extent of disability, experience with the service system and the other environmental challenges they confront.

5. Many individuals with disabilities have not had their self-determination supported by their family members, however some family members have been major allies for self-determination. We should be cautious in over-generalizing and assuming that all families are unsupportive.

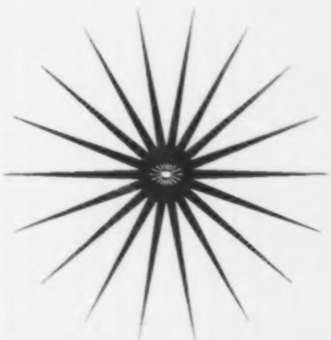
6. Many factors, such as traditional societal expectations that families should be responsible for the lives of individuals with disabilities and a lack of professional and system support, have made it difficult for many families to support, and individuals to express, self-determination. We need to learn more about the barriers that families and individuals have faced and what they believe would increase their support for self-determination.

7. The foundations for self-determination are laid in the earliest years. Therefore, families should be made aware from the earliest years of ways to facilitate the self-determination of their children with disabilities.

8. It is in the best interest of the national self-determination movement for cross-disability individual and family leaders to build a common vision for self-determination.

9. Individuals with disabilities should have the primary national leadership role in setting the self-determination agenda, and family and individual leaders should work together to move the agenda forward.

10. Disability organizations should make self-determination a priority, including focusing on it in their conferences, publications, advocacy and research, and looking at ways to promote partnerships among individuals and families.



Living the Questions:

What happened to me during Action Learning, or a description of the evolving process and some thoughts along the way

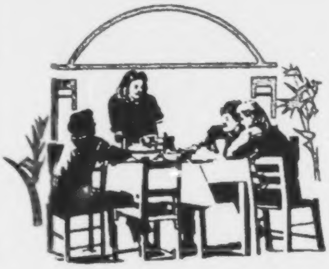
BY MARY BETH PAUL

In March of 2000 I was invited to participate in an "Action Learning Group" with a handful of other mothers from central Ohio. The facilitator, Candee Basford, was another parent who had been involved with a grant funded through the Ohio Developmental Disabilities Council called "Removing the Mask." Among other things, this grant was helping small local initiatives make grassroots changes around long-term needs for their children with disabilities. Barb McKenzie, a local "activist" parent, invited me to join this particular group because we all had ongoing concerns about inclusive education and advocacy, especially self-advocacy.

I already knew four of the five other participants; all of us had been in different leadership positions around advocacy, education, disability rights, both paid and/or volunteer, in our community. Including the facilitator, five of the seven that made up the entire group have children with Down syndrome. All of us have had at least some success including our children in public schools; most have had their children fully included. When Barb called me to get together, I was not exactly clear what we were going to be doing. I just knew that I was being invited to spend time with some other parents and talk about what was going on with school, about successes and struggles. I also heard "we'll be having something to eat and there will be wine, so get a sitter and plan on a great evening."

My curiosity was piqued. Four of these women I considered the "inclusion goddesses." They seemed to have set the standard (and very, very high ones they seemed to be) for including their children with disabilities in regular education settings instead of segregated programs. I had felt ambivalent a lot of the time whether or not this was truly possible for my family, given the behavioral challenges my son was presenting at school every day. I made a promise to myself that I would be honest with these women about my huge concerns, doubts and fears. But I also just wanted an interesting evening with good conversation and a chance to gab in a relaxed atmosphere.

What happened at that first evening was simply different and familiar at the same time from any gathering I had been to before. The best part about it was that it was intimate and relaxing. We met in the hotel suite that the facilitator had booked for the evening, since she was from out of town. We were able to light candles, eat homemade soup and other comfort foods, eat some chocolate, and share a few bottles of wine. No kids, telephones, or crises to deal with. No interruptions. From that standpoint alone it was a real getaway.



After we all introduced ourselves and/or brought each other up to date about children, families, and jobs, we began the work of the meeting.

The simple question that we each were asked was "What is the one burning question in your life?" That was pretty quick and to the point. And since we were gathered there around our children's situations, my question was "How do I include my son if he doesn't want to be included?" (My son had not been able to deal with being in second grade at the time; he had been very disruptive. He was still displaying aggressive behaviors in the special education class, as well. We were truly at odds about what to do.) As everyone went around and shared their "burning questions," it became clear that there had been no straightforward path for anyone about what to do for their children. I listened most carefully to the woman whose daughter used to have some aggressive and disruptive behaviors when she was younger. This soft-spoken and eloquent mother talked about just taking a year off from trying to do things perfectly; about creatively approaching things; about getting different people on board to help.

The facilitator had excellent listening skills. She never dominated, but knew how to connect people's questions one to another. We, too, were to listen respectfully and without making judgments. As people spoke, she wrote with words and colorful graphics. This kind of non-verbal response also provided us with her interpretation of "What I hear you saying is..." She might draw yellow "rays" around a word to connote energy or warmth; a house with a heart around it gave more emphasis to the meaning of home, and so on.

As I stayed true to my promise to myself to be honest with them about my struggles with my son, I felt that people really were listening to me. As I listened to the others, I heard more honesty about the difficulties all

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of us shared. No one had a monopoly on the "right answers."

We then went around again and shared some possible actions we could take around our questions. We were to come back to the next meeting (about a month later) and share something about our actions. We were also to bring a gift. This was a nice, open-ended thing to do. There were no other instructions about what that meant.

Before the second meeting, my uncle who had been institutionalized for a period in his life but had come back home (with various supports), had died. I attended the funeral and then wrote an essay about him and his impact on my life. That helped me bridge my past with my present life with my son. This was my "gift" that I brought to the second meeting. Being able to share my reflections with others who were also struggling with life-long questions was quite cathartic for me. Because people were willing to hear me out, I felt like a broken dam with my life pouring out at times.

Over the course of several months, we continued to meet. The food and drink was clearly an important part of the meetings. I loved that it felt like we were involved in parent support and advocacy, but I loved that it was something that I looked forward to instead of dreading. (Other groups that I had been involved with meant mailing lists and fund raisings and programs and committee meetings.) Action Learning was a total group of seven; e-mail and phone calls connected us in-between meetings; no dues and no agenda but the gentle constructs of the Action Learning format of question-action-reflection-question-etc.

> The shared experiences, storytelling, reflection and gifts...fosters caring, listening, "wasting some time together," and even silence. It is not how to do things the "right way," but rather, "how can we think about this problem together?"

As our group formed a closeness, we began to tell more stories about our children. Sometimes these were just delicate, fragile vignettes: a triumph of a new skill achieved; the courage to try something a different way; an unexpected guest who wanted to play with my son. I found that hearing all- the failures and the successes- was extremely important to me.

As time went on, I found myself more apt to call someone from our group for help or feedback when something really tough was happening. I found myself listening a lot more carefully to other people's questions. I found myself listening more carefully to all kinds of questions, not just those about my son.

Because this Action Learning group was funded by the Ohio Developmental Disabilities Council, I received invitations to other workshops they were hosting. Connie Lyle O'Brien facilitated our final meeting and gave us wonderful feedback. I found myself at a Self-Advocacy workshop given by John O'Brien, and there I felt a reconnection to old friends from my past.

Candee, our Action Learning facilitator, also brought Jo Krippenstapel into my life. Jo has since helped me think through some very difficult aspects of my son's behaviors by connecting me to others who are continuing to help.

Since one of the major parts of Action Learning is asking the questions, something that flowed from our group was simply asking more and more questions that don't necessarily have answers. And thus, in the reflection, I am learning to live more comfortably in the gray areas.

In this kind of atmosphere, we found ourselves being gentler with one another. During this time of about four months, some of our group experienced life threatening illnesses, long-term care for extended family, and major life transitions. Seeing the changes in the other members as they dealt with these things was humbling and moving.

Also during this time I seemed to experience a kind of opening up of a dimension that had been closed off to me for many years. I was suddenly meeting people who were asking the same kinds of questions. I was bumping into old acquaintances who were talking about getting together to meet and work on problems in the school district. I was somehow getting connected to more helpful and supportive people than I had met in years. And through it all I tried to listen more carefully to the questions they were asking. I found myself being able to connect other people, as well.

What has come out of all of this? Well, I felt like I had the energy to get something going with friends who had been asking some of the same questions as our original group. So Barb and I started a second Action Learning group consisting of more parents who have or had been active in leadership roles around disabilities in our community. We have met four times now. We came to the realization that we need to support one another, but didn't want to go back to the same old programmed meeting format. This has been supported by the "Removing the Mask" grant, as well.

I started to read again about disability-related issues, both philosophical and practical. I also subscribed to an on-

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line listserve about inclusion as well as the TASH listserve. I attended a PATH and Creative Facilitation workshop. There I was able to make more connections, as well as reconnect again to people and events from my past. I also attended the national TASH convention last December.

Through all of this, my family has had to weather a very difficult school year for my son. He started at a new school, with just about all new students and staff. He reacted very strongly against these changes that were imposed upon him, with aggressive actions and disruptions such as screaming. People at school were at a loss as to what to do after attempts to deal with my son the same old way yielded little success.

I felt much more able to ask for help from members of my Action Learning group. Some of the help came in the form of being able to vent safely; some came in the form of "why don't you call so-and-so?" Some came in the form of learning that reframing a problem can yield different solutions. Some help came from thinking about others' stories: if we can weather this, then we can keep our eye on the long-term prize: more language, more friends, being more a part of the community; more self-control, more fun; more meaning and a more interesting life.

Because of Action Learning, I asked our school district to ask for more help. This yielded enormous results: our team now has on board someone who understands autism, team facilitation, non-verbal communication strategies, and sensory issues. We are all gaining a better understanding of what might be making my son tick.

But what else has come out of this has been a way to connectedness to many other things in life. Questions to think about concerning our local community; around use of material goods; around inherent value in things; thinking about the meaning of community; watching this format called Action Learning evolve.

Action Learning is actually a tool of sorts, a social construct, used by business and management to help groups work more productively, more effectively, and with greater quality. John O'Brien has used it with medical employees in England. He suggested the format to some folks in Ohio as a way to work on supporting families at the local level. Thus, it is being used now to facilitate change around issues such as inclusive schools and communities, self-advocacy, and other social action issues. Groups have consisted of all parents (such was my group) and school staff. Candee Basford has continued to be the main person facilitating these groups, saying that her goal is "to change the world, one conversation at a time."

Candee is fascinated with the process; we engage in a dialogue around that. Barb offers many ongoing opportunities to continue to think about new ways to approach the old questions. I am astounded at the effect that this has had on my intellectual and spiritual life. My husband and I have found a mutual bridge on which to meet about our challenges with our son Peter Ben, and he and I are able to talk much more easily about the "what do we do next." And as we continue to discuss, Peter begins to plan how he can get his university students in education to engage in more reflection, as he, Barb and I formed a mini-Action Learning trio.

For me, Action Learning has put me in mind of a "Holy Way." First, the format reminded me of church liturgy planning meetings I used to be involved with. This was a chance to read-reflect-share-reflect-discuss and then form consensus.

The shared experiences, story-telling, reflection, and gifts brought to mind planned retreats that support conversion and community such as "Christ Renews His Parish" and "Renew." The form of small, grassroots groups working mutually to support one another is also similar to "base communities," which first began in Central America as an outcome of Liberation Theology. It is Church that is decentralized but supportive of small households gathering regularly to eat, pray, and play together apart from Sunday worship.

What Action Learning is not is rigid, top-down (with a leader who teaches or preaches) or absolute. It fosters caring, listening, "wasting some time together", and even silence. It is not how to do things the right way, but rather "how can we think about this problem together?"

> In the end, while our children with disabilities may be the reason we came together, we ultimately are people needing each other, finding in each other a helping hand to make a better way for our children. In doing that, we make a better way for ourselves.

Action Learning also goes against the grain of the current cultural values. It is not particularly efficient, since only a few people at a time meet together. It won't make anyone rich quick, since it is more about being than doing, although

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the doing follows from being together. It fosters silence and quiet, not business and a full agenda. It requires interdependence, not independence. It gives us a way to live with the unknown, to stay in the moment. Most of the changes seem to occur between the meetings; in a Zen-like way, it is the "not meeting" time that yields the true outcome or work.

No matter what one's religious affiliation or spiritual inclination, this kind of work is in line with the commonly held tenets of many faiths that values a time apart for prayer, reflection, meditation, contemplation. It acknowledges a dependence on the Other. In sharing food, there is a way to celebrate and nourish more than our bodies. In telling stories, we begin to write a history together.

In the end, while our children with disabilities may be the reason we came together, we ultimately are people needing each other, finding in each other a helping hand to make a better way for our children. In doing that, we make a better way for ourselves.

Resources

During the process of attending Action Learning meetings and beginning to facilitate a new group in late 2000, I corresponded frequently with Candee Basford about the process itself. She forwarded many links, references, and quotes as we continued the discussion about the role of the facilitator, how to support reflection, the importance of the meeting environment, etc. Among the most helpful:

Action Learning: A Guide for Professional, Management and Educational Development. Ian McGill and L. Beaty. 1995

At <http://www.leaderscircles.org/theory.htm> is the the following publication: *Dynamics Underlying the Peer-Based, Action Learning Process* by Carter McNamara, MBA, Ph.D.

An excellent description of Action Learning can be found at <http://www.simmons.edu/gsm/cgo/projects.html>; Scroll down to the project CGO Change Agent Action Learning Forum (Research/action learning project).

Further along in the description "action learning" is highlighted. If you click on this, it will take you to the paper that was a product of this project, *EXPLORING ACTION LEARNING* As developed by the CGO Action Learning Project Team, May 2000 (c)2000 Center for Gender in Organizations, SIMMONS Graduate School of Management, 409 Commonwealth Avenue, Boston, MA 02215-2380. This document may be linked or reproduced for non-commercial purposes provided the author(s) is cited and the copyright notice is visibly displayed. All other uses must be approved in writing. This will open with Acrobat Reader. At the end of this paper is a print bibliography.

Questions and comments about this article may be sent by e-mail to Mary Beth Paul at <paul.3@osu.edu>

The author would like to express deep appreciation to Candee Basford for sharing her belief that "we can change the world, one conversation at a time." She has been a friend and mentor, sharing the information and links about Action Learning and assisting in preparing this article for publication.

The author also thanks Barb McKenzie for setting it all in motion with an invitation to get together -- with one conversation leading to another!

Ticket to Work and Work Incentives Improvement Act: Concerns and Recommendations

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payments, significant savings are available to SSA through partial employment of individuals who for health or personal reasons are unable to work on a full time basis. The regulations should provide an option for outcome payments based on a significant reduction in SSI case payments. Such a payment system should be based on clear benchmark employment levels, and not a gradual reduction to retain simplicity.

Recommendation:

- Establish a demonstration program that provides outcome payments at half the level of the full outcome payment system for individuals who are working at 50% of SGA or better, provided that an individual's employment plan clearly justify a reason for the reduced level of employment.

Individuals will need clear and consistent information to assist them in choosing among Employment Networks.

Recommendations:

- The regulations should specify both the information to be provided to prospective consumers by Employment Networks, and the format that the information is provided in. This information should be simple and clearly based on the effectiveness of the organization in assisting individuals to achieve employment including a description of individuals served, the percent of individuals entering employment, the employment outcomes they achieve, and the capacity of the organization (number served).

Do We Really Mean Families for All Children? Permanency Planning for Children with Developmental Disabilities

BY NANCY ROSENAU

Though family support has become the dominant form of services for children with developmental disabilities, nonfamily residences still exist for these children. The statement that "all children should grow up in families" is far from including all children. Permanency is a concept that seeks to assure a permanent family living situation for children. Permanency activities include family preservation, family reunification, and finding alternate families for children who cannot remain with their birth families.

Twenty years have passed since permanency became accepted practice in child welfare. Ten years have passed since the call went forward for its application to children with disabilities. Yet, permanency policy has yet to be embraced as an imperative in services for children with disabilities. Following is a discussion of some of the impediments to implementation of permanency.

There is a significant disparity between the rhetoric that "all children belong with families" and the reality. There is great variability nationally. Eight states reported 10% or more of their large facility residents as 0-21 years of age (Anderson et al., 1999, p. 5), while seven states operate no large state facilities. Five states report more than 450 children under age 18 living in public or private institutions of 16 or more beds (Hemp, 2000). While the impediments each state experiences are complex, three common beliefs are present in the folklore of difficulties expressed at the "street" level of implementation of permanency policy: some children cannot live with families; alternate families can't be found, and birth parents won't accept another family.

Misconception: Some children cannot live with families. While there is broad consensus in favor of children with milder disabilities living with families, skepticism that children labeled with more severe levels of impairment can live with a family is part of our folklore. The impression, sometimes stated outright and sometimes merely implied by our practices, is that some kids are "just not family material." This myth is best dispelled by the fact that a child labeled with every kind and severity of disability is currently living successfully with a family. While one family finds a child's needs too great or their lifestyle too restricted, another family with a child with identical labels is doing well. The disability alone is not the reason for nonfamily life. We must look beyond the child for an explanation. A more complex understanding leads to consideration of two broad areas: (1) the nature of supports to families; and (2) the recruitment of alternate families.

Family support has grown dramatically in the past decade. Yet, as dramatic as the increase is, it falls far short of the needs of some families. Tremendous differences exist among the states in the level of their commitment to supporting families. Clearly, a commitment to families as a priority requires a commitment to funding and designing supports that will provide whatever it takes to make that possible.

Misconception: Families can't be found for children with significant disabilities. When no amount of resources or creativity will make it possible for a child to remain with her or his birth family, then an alternate family needs to be found. There is a common belief that, however desirable, alternate families cannot be found for some children. The evidence usually cited to support his claim is the difficulty that child welfare systems experience in finding enough families. As the logic goes, if you can't find a family for typically developing children, then you surely cannot find a family for a child with severe disabilities. This logic fits the negative societal image of disability as something no one would voluntarily seek, and its corollary that a person with a disability is someone no one would voluntarily include in her or his family or close personal network.

This mistaken belief is dispelled by three sources of evidence:

1. An estimated 1.9 million individuals with developmental disabilities live with families (Braddock et al., 2000, p. 41).

2. At least 6,000 children with developmental disabilities live with foster families (Hemp, 2000).

- Alternate families are successfully recruited by organizations that have devoted significant energy to the process.

> Both our policies and our practices for children with developmental disabilities are too little directed to permanency. Parents who are respectfully engaged in a discussion of permanency can and do seek to place their children with other families. Where supports are inadequate or no alternate families exist, families may represent the only alternative. Where facilities exist without viable alternatives or no opportunity is offered to work through reluctance, parents may "choose" a residential facility. That is not a choice, but a default position.

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Permanency Planning for Children with Developmental Dsabilities

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The availability of alternate families is directly related to the energy put into seeking and preparing them. Where energy has been great, families have been found. Where families have not been found, energy has either not been great, has been diluted by competing responsibilities, or has employed ineffective strategies. The success of program like Macomb Oakland Regional Center in Michigan (Taylor, 1991) and Every Child, Inc. (formerly Project Star) in Pennsylvania (Taylor, Racino, Walker, Lutfiyya, & Shoultz, 1992) in finding families for large numbers of children with severe disabilities gives testimony to its feasibility. The fact that the MR/DD agencies in nine state report no children with developmental disabilities under age 18 living in facilities with over 16 beds, and over 1,000 children (in aggregate) living in foster care, gives testimony to the feasibility of family residences (Hemp, 2000).

Misconception: Birth families won't accept another family. As the logic of this misconception goes, even if alternate families could be found, birth families will not accept them. It is true that many birth families initially believe that if they who love their child cannot continue to have her or him live at home, then no other family could either. At first blush this seems reasonable and logical. It is dispelled, however, by the fact that many families do come to accept that an alternate family can raise their child. Experiences in Michigan, Pennsylvania, and elsewhere have provided clear practical advice about how to handle the emotionally charged and potentially conflictual issues involved in coming to this acceptance. These experiences have helped develop successful strategies since the mid-1980s, strategies that have, however, seen relatively little generalization.

Experiences of places such as Macomb Oakland Regional Center and Every Child, Inc., where alternate family placement is made by voluntary agreement with the birth family, demonstrate the feasibility of this approach. A closer look at their strategies finds three important elements at work: (a) high quality alternate families are readily available; (b) the relationships between the birth family and the person who works with the birth family is carefully built through trust and longevity; and (c) the birth family retains the decision about a particular family for their child.

The process of conversion from reticence to acceptance involves helping the birth family to see how an alternate family differs from them. Presenting the possibility of alternate family care requires an explanation of how another family can do what a loving birth family cannot. This involves pointing out differences such as the choice to raise a child with a disability, the choice of type of disability, preparation prior to having the child, and beginning at a peak of readiness and energy. While those differences can make alternate family care more palatable to consider, experience has shown that the real convincing comes when the birth family is introduced to a particular alternate family. If the recruitment process has been done well, the very attributes of the alternate family will be apparent. In the experience of Macomb Oakland Regional Center, hundreds of birth families have made the choice voluntarily.

The family support movement calls for recognition that families are competent. Families can make responsible decisions about permanency, but questions about permanency need to be posed. Too frequently parents are steered toward residential placements by professionals who are themselves reticent to confront the issues. Parental choice of a residential facility cannot be treated simply as a preference out-of-context with its permanency implications. Failure to address permanency is a disservice to the family as well as the child. Parents who are respectfully engaged in a discussion of permanency can and do seek to place their children with other families. Where supports are inadequate or no alternate families exist, families may represent the only alternative. Where facilities exist without viable alternatives or no opportunity is offered to work through reluctance, parents may "choose" a residential facility. That is not a choice, but a default position.

One problem is that facilities for children exist. By their very existence they come to be justified and admissions continue. When a family is struggling, rather than reviewing which facility is most appropriate, the issue should be with which family the child should live. That review is related to what kinds of support a family can accept. Which family can accept the child and the child's needs and the challenges that may be required to meet the child's needs and the lifestyle that accompanies the challenges? Permanency planning will help to sort out what the birth family needs and when an alternate family is needed. Permanency planning will help sort out how birth and alternate families will relate to each other and share in making a secure family home for every child. Respectful but assertive exploration of permanency can allow a mutually satisfying arrangement that fulfills the vision that all children grow up in a family.

Reality: Lack of data hampers policy assessment. The acid test of permanency is how many children do not live with permanent families. We currently

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have no systematic way to track children with disabilities in order to judge the security and nature of their family situation. We do not reliably know how many children do not live with families. Our data keeping is not organized to indicate whether children live with families and whether their family life reflects permanency principles. None of the readily available national data sets tracking trends for persons with developmental disabilities clearly identifies the total number of children living in non-familly settings.

Over the past 20 years, data collection on a national scale has improved dramatically. Data collection not only identify trends, it steers them. By asking questions at a national level, agendas are set and priorities are identified. What is asked, and what is not, tells much about what is considered important in developing services for people with disabilities. If we don't track where children are, we are less able to judge how well our systems are doing in providing for permanency for children with developmental disabilities to assure all children grow up in a family.

Conclusion and Recommendations
Both our policies and our practices for children with developmental disabilities are too little directed to permanency. The United States as a nation and individual states should invest in permanency. They should:

- Adopt permanency as a policy for all children.
- Include permanency policy within family support policy for children with disabilities.
- Assure implementation of policy through mechanisms to track non-family placements of children, require a written permanency plan for all children served, and require periodic administrative review of permanency plans and non-family residential placements.

State, local governments, and service providers should invest in relationship-based family support. They should:

- Review policies that inhibit relationships.
- Support strategies that enhance relationships.
- Increase the match between needs and responses.

States, local governments, service providers, and advocates should invest in alternate family recruitment. They should:

- Recognize the protracted process involved in family decision-making.
- Provide dedicated energy to recruitment.
- Disseminate successful strategies.

All stakeholders, policymakers, advocates, and community members should work together to connect permanency, family support, and alternate family recruitment as inseparable elements of policy and practice to assure a family home for all children.

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Survivor Promotes Ideology of Exclusion

BY LAURA HERSHEY

This article was written during the first season of the CBS program, "Survivor."

I just found another reason to kill my television. But I probably won't. For me, TV is more than just electronic entertainment. It's a source of insight, and stress. It's a 32-inch window looking straight into our nation's soul. I don't always like what I see there. But I can't seem to look away.

TV's latest offense is the CBS series called "*Survivor*." It's part of a strangely popular entertainment genre called "reality television." That's a misnomer: the central situation of *Survivor* is about as far from the average American's reality as "The Wizard of Oz." How many viewers can relate to the experience of being placed on a desert island with a group of strangers, and having to compete in various bizarre competitions like raft races and gross bug-eating contests? The "reality" part means that instead of paying actors, the show uses regular people.

Despite its non-existent grip on reality, *Survivor* seems to have caught the public's imagination, rewarding CBS with high ratings, aiding the network's financial survival. The show has become fodder for workplace gossip and David Letterman jokes. It has taken on a life of its own on the Internet, spawning dozens of fansites.

Why is the show so popular? An exotic location, a diverse mix of personalities, cooperation and competition, winners and losers. It's perfect summertime fare, dramatic and fun, if you don't think too hard about it. That's my problem: I think too hard about it.

When I watched the first two episodes, I could see those exciting elements. I knew *Survivor* would be a hit. But I also found watching it profoundly uncomfortable. At first, I couldn't understand why the show bothered me so much. My first, inarticulate critiques were that the show was "stupid" and "contrived." But that describes about 90 percent of what's on television. There was something about *Survivor* that disturbed me more than usual.

Over the next few days I began to understand my visceral reaction to the show. I saw a carefully-developed message emerging from the very first episode. It's a message that I, as a disabled person and an advocate for people with disabilities of all ages, have every reason to fear.

Here, in a nutshell, is the message: The strength of a group depends on, and justifies, getting rid of its less powerful members. That same theme has been carried throughout the series. The point is driven home in every episode, quite deliberately and bluntly. Camera angles and music help to heighten the drama, evoking the prescribed mood for each event. Although the cameras do capture spontaneous interactions and responses from the island inhabitants, or contestants, or whatever you want to call them, there's nothing accidental about the show. Through explicit rules, elaborate rituals, and deliberate editing, the program presented to us is exactly what the producers want it to be — namely, a tribute to our country's most punitive social and economic policies.

> **Communities aren't communities if they exclude anyone. It isn't physical prowess or cutthroat competition that makes a society strong; it is solidarity, the ability and willingness to include everyone in the ongoing life of the community.**

Blending sophisticated production techniques, *Survivor* pulls us, the viewers, into an adventure. Then, while it's got us riveted to the screen, it seduces us into participating in an insidious selection process. Ask anyone who has watched the show, what is the most gripping and memorable part of each episode? It's the "tribal council" meetings, where a group must decide which of its members to send packing.

The final vote, where one person is deemed unfit to stay, becomes the compelling climax of each hour-long segment of "*Survivor*." As each individual enters the "voting confessional," we hang on every word of their pseudo-private reflections. We hear them considering the undesirable traits of whichever of their companions they have decided to reject. They use terms like "weak link" and "not contributing."

This process of deciding whom to eject is clearly the show's main attraction. That's what gets people talking. The fansites are full of invitations to "click here and vote on who should be the next survivor to be eliminated." Viewers are irresistibly drawn into the *Survivor* dilemma: Which members of the group are assets, and which are liabilities? Who should stay, and who should go?

As we follow the series from week to week, we viewers are seduced into accepting the show's unspoken essential

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premise — that in order for a society to be strong, to survive, certain individuals may have to be expelled. The process of voting people out is presented as harsh, but necessary. As each "tribal council" meeting begins, each participant lights a torch and places it ceremoniously next to his or her seat, while the rather obnoxious host of the show explains soberly that the flame "represents your life, your identity." Then, when the final vote results are announced, the unlucky outcast must extinguish his or her torch and disappear into the jungle, never to reappear in that community again. Thus, the weak link of the week is not only banished, but metaphorically killed. Their flame, symbol of their life, is snuffed out by majority vote.

My own revulsion at this show, I think, arises from my suspicions that on some level, it's sending a message that I've heard before. People with disabilities, in particular, have often been singled out, branded unfit, and sent away. Nursing homes and other institutions are full of people, young and old, who have been essentially banished because they cannot function with complete self-sufficiency. Rather than support these people in living in their own homes and communities, public and private health agencies, and even families, choose to relegate people with disabilities to human warehouses.

In some quarters, disability is seen as a crime deserving not only confinement, but death. Jack Kevorkian received a "citizen activist award" from a supposedly progressive foundation. His contribution to human progress? He helped to kill over 100 people, most of whom had non-terminal disabilities. It is true that these people requested "suicide assistance" from Kevorkian; but if they had been able-bodied, and depressed over some situation other than disability — divorce or unemployment, say — their request would not have been considered a mitigating factor. Kevorkian would have been prosecuted and convicted much earlier in his career had he been killing people without disabilities. His victims were denied the equal protection of the law simply because their health status got them branded undesirable members of society.

What does all of this have to do with *Survivor*? No one on the island has an apparent disability. This is a notable omission, given that the show's producers obviously put a great deal of effort and thought into creating a diverse group. The cast of castaways includes several African-Americans, an "out" gay man, a range of occupations from doctor to truck driver, and a group of hearty women who don't shrink from building fires or eating vermin. Given the difficult living conditions and the demanding "challenges," it goes without saying that a person with a physical disability wouldn't make it. Perhaps the producers wanted to avoid a scenario in which someone with multiple sclerosis, or blindness, had to be voted off the island. It would seem cruel and politically incorrect. It would make the show's harsh philosophy just a bit too apparent.

Nevertheless, I am guessing that variances in physical ability will be an undercurrent throughout the series. The line between ability and disability will be thin and constantly moving. A contestants' survival will often depend on which side of that line they're on during that particular episode. In the debut episode, the democratically-elected loser was a woman who consistently demonstrated compassion and cooperation, but who sprained her ankle and fell during the group challenge, slowing down her team. From the moment she showed such weakness, her fate was sealed. Her companion-competitors started talking about how she was "holding back" the group. I will not be surprised if variations on this theme recur repeatedly during the series: If you can't keep up, you've got to go.

I can't help thinking it's no coincidence that *Survivor* appeared at this point in history, when powerful economic interests are promoting an agenda of scarcity and denial. Civil rights laws like the Americans with Disabilities Act come under attack as a threat to business growth. Corporate welfare subsidies enrich the rich, while already-underfunded public health, education, and income support programs come under attack as a drain on society. Increasingly, poverty is viewed as a personal failure, a criminal act deserving punishment. Discrimination is dismissed as paranoia. These attitudes result in denial of help — or, more to the point, justice — to poor people. That frees up more resources for the rich and powerful.

Or, to look at it somewhat more optimistically, perhaps we are seeing a backlash against recent progress in social justice. The disability rights movement has achieved a few modest gains in making society more accessible and accommodating. For every step forward, we meet resistance. Children with disabilities have a federally-guaranteed right to be educated in regular classrooms with appropriate supports; but parents of nondisabled children often object that the presence of a student with learning disabilities will detract from their own "normal" child's educational experience. In the midst of these escalating social conflicts, there now appears a game show — mere harmless entertainment. It's fun and gossipy, so we don't question its underlying principles. But the rules of this "game" seem designed not just to reward the winners — that's an expected part of any game — but especially to punish the losers.

Somehow, I realized this game seemed eerily familiar to me. I remember exercises I participated in during adolescence — several times at church youth camp, once in a high school class

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— called "values clarification." This involved a group discussion about making difficult choices in some hypothetical adverse situation. As I recall, these exercises were supposedly intended to help us understand our own beliefs. That sounds benign, even enlightened. But in reality, I remember I often felt deeply troubled not only by the outcomes of these discussions, but also by their instigation.

A typical example: My peers and I were told to imagine being stranded on a lifeboat, along with an assortment of strangers and a dwindling supply of food and water. Our companions on the boat included a young pregnant woman, a surgeon, an unemployed drifter, an elderly man, a Boy Scout, a woman with cancer, and so on. The setting and the cast of characters varied, but the basic idea was that some people would make it, and some people wouldn't — and that it was up to us to decide, based on what we thought of the relative value of each fictitious person.

I never had much to say during these discussions. When they were over, I often had a queasy feeling that stayed with me for several days. I never fully understood why, until much later, as an adult. I gradually came to understand that these so-called "values clarification" exercises were based on a preordained set of values, which I could not accept. The games assumed that there weren't enough resources to go around, and that some people have more value, more right to live and to consume resources, than do others.

As a kid with disabilities, these assumptions — and the conversations they prompted — made me nervous. Perhaps I was already acquainted with the idea that some people just don't belong. Years earlier, my parents had had to battle the local school board to get me placed into a regular classroom, rather than in the ineffective "special ed" setting where I had spent my first two years. Since then I had thrived academically, and we never regretted the hard-won change. But occasionally I still found myself at odds with other people's attitudes. I remember, in particular, a journalism teacher who consistently discouraged my ambitions. When I applied to be editor-in-chief of the high school newspaper, she made me features editor instead, even though I had more experience and skill than any other journalism student. Then a friend told me about a casual conversation her mother had had with this teacher. The teacher told this acquaintance that I should not be in her classroom at all, but should be in a "special" school instead. I can still recall the horror, confusion and shame I felt when I heard her views stated so blatantly, even from a secondhand source.

Such attitudes have not disappeared. I continued to confront them as an adult. I once found myself debating the merits of the Americans with Disabilities Act (ADA) with a belligerent radio talk show host. He was furious that government dollars would be spent on adaptations like ramps, elevators, and telephone devices for the deaf. I pointed out that we all use structures and services paid for from the public coffers. I mentioned highways and schools. This really raised his self-righteous ire. He blustered, "The difference is, I am a net tax payer, while YOU are a net tax user!" His easy use of this terminology told me that it was not a concept he had invented on the spot; clearly, his worldview was based in large part on this neat division of the population into two groups: those who contribute to society, and those who only take from it. I might have been shaken by being placed on the wrong side of his harsh dichotomy, as I was by my high school teacher's prejudice. But by then I had developed a worldview of my own — a worldview, shaped by the disability-rights movement, very different from that of *Survivor.*

In the disability rights community and other social change movements, I have seen genuine efforts to create sustainable societies — efforts that could teach those TV "survivors" a thing or two. There are so many ways to contribute to a group effort, and every person can be valuable if given the opportunity. I've seen people with severe disabilities, who grew up in institutions, who were denied any chance for a formal education, who by conventional standards had few skills and no power — and watched as these same people evolved into true leaders. They were not leaders in a competitive or domineering sense, becoming winners by making other people lose. Rather, they commanded respect for their own unique qualities.

Perhaps we all live on an island of some kind, with our own assortment of companions. On my island, which is to say my conception of society, everyone belongs. Everyone contributes. Everyone is absolutely necessary, until natural events or their own choices take them somewhere else. Some of them earn admiration for their devotion to the cause, their willingness to perform seemingly "menial" tasks with good humor and utmost dignity, to help the success of a campaign. Some find and nurture innate talents for art or music or political theory, and use those talents to strengthen their communities. Some simply live their lives, defying all attempts to exclude or marginalize them, and in doing so they model an ideal to which we can all aspire; this may be the greatest contribution of all.

Communities aren't communities if they exclude anyone. It isn't physical prowess or cutthroat competition that makes a society strong; it's solidarity, the ability and willingness to include everyone in the ongoing life of the community. We're all in the same lifeboat — planet earth — and no one can be voted off. Now that's reality.

Laura Hershey is a disability rights leader, poet, writer and trainer. For more information on Ms. Hershey's work, please visit her new web site address, http://www.cripcommentary.com

The Convention on the Rights of the Child: An Overview, an Update, and a Challenge

BY ANNE SMITH
and
ZUHY SAYEED

"Human rights are inscribed in the hearts of people; they were there long before lawmakers drafted their first proclamation."
Mary Robinson
U.N. High Commissioner for Human Rights

This TASH Connections report provides an overview of the Convention of the Rights of the Child (CRC), an update on CRC implementation issues, and a six-point agenda for inclusive disability policy for the CRC and a rationale.

An Overview

The Convention on the Rights of the Child (CRC) was carefully drafted over the course of 10 years (1979-1989) with the input of representatives from all societies, all religions and all cultures, and was based upon varied legal systems and cultural traditions (http://www.unicef.org/crc/introduction.htm).The Convention has been ratified by 191 countries and protects children's rights by setting standards in health care, education and legal, civil and social services. These standards serve as benchmarks against which progress can be assessed. States that are party to the Convention are obliged to develop and undertake all actions and policies in the light of the best interests of the child.

Like all human rights treaties, the CRC first needed approval or adoption by the United Nations General Assembly. On November 20, 1989, the U.N. General Assembly adopted the CRC into international law. All recognized nations around the world, **except for the United States and Somalia**, have ratified the Convention on the Rights of the Child, pledging to uphold its protections for children. Today, the Convention on the Rights of the Child is the single most widely ratified treaty in existence.The CRC recognizes that children have the right:

- to be free from discrimination;
- to be protected in armed conflicts;
- to be protected from torture or cruel, inhuman, or degrading treatment or punishment;
- to be free from arbitrary deprivation of liberty; to special treatment within the justice system; and
- to education, health care, an adequate standard of living, and freedom from economic exploitation and other abuse.

The CRC consists of 54 articles that incorporate civil and political rights as well as economic, social, and cultural rights of all children. The CRC is grounded by four underlying values or "guiding principles" :

The first 41 articles outline the human rights to be respected and protected for every child under the age of 18 years, and require that these rights be implemented in accordance with the Convention's guiding principles. Articles 42-45 cover the obligation of States Parties to disseminate CRC principles and provisions concerning implementation and monitoring of progress towards the realization of child rights obligations, as well as reporting responsibilities. The final clauses (articles 46-54) cover the processes of accession and ratification by States Parties; the Convention's entry into force; and the depositary function of the Secretary-General of the United Nations.

Four guiding principles of the Convention on the Rights of the Child

1. Non-discrimination (Article 2)
2. Best interests of the child (Article 3)
3. Survival and development (Article 6) and
4. Participation (Article 12)

Article 23 is the only one that specifically addresses disability and its four provisions state:

○ States Parties recognize that a child with mental or physical disabilities should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

○ States Parties recognize the right of the child with a disability to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child.

○ Recognizing the special needs of a child with a disability, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

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○ States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of children with disabilities, including dissemination of and access to information concerning methods of rehabilitation, education and vocational services, with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of developing countries.

For more detailed information on the Convention on the Rights of the Child including protocols, process, protection and monitoring, please visit <http://www.unicef.org/crc/introduction.htm> and/or <http://www1.umn.edu/humanrts/instree/k2crc.htm>

An Update: Ten Years of CRC Implementation

In the decade since the adoption of the CRC some significant advances have been achieved for the world's children. For example, many countries have used the CRC as the basis to revise domestic legislation to improve protections, or have appointed special ombudspersons or envoys for children. The Committee on the Rights of the Child is the body responsible for monitoring compliance of states to the convention, has evaluated country reports under the convention by developing standards of protection, and has pressed governments for specific reforms.

However, Human Rights Watch (1999) reports that, *"Children living outside war zones may also be subjected to routine violence. Street children on every continent endure harassment and physical abuse by police. Even schools, intended to promote the healthy development of children, may be the site of abuse against children. In some countries, the use of corporal punishment by teachers has resulted in injury and even death. In others, gay and lesbian students endure harassment and violence by their peers, while school authorities fail to intervene. Millions of children have no access to education, work long hours under hazardous conditions, or languish in orphanages or detention centers where they endure inhumane conditions and daily assaults on their dignity, in violation of the rights guaranteed to them under the convention."* <http://www.igc.org/hrw/press/1999/nov/children.htm#_1_10>

The plight of orphans and abandoned children should be of particular importance to TASH members. According to Human Rights Watch (1999), an unknown number of children, most likely in the hundreds of thousands, if not millions, are kept in orphanages and non-penal institutions throughout the world. Many of these children are subjected to abuse and neglect and have been abandoned because their families are poor, jobless, ill, or in trouble with the law. In some instances, medical personnel pressure parents at birth to give up children born with disabilities, claiming that parents will be ostracized for raising a child with a disability. And in countries that have restrictive population control policies, or where cultural traditions value boys more highly than girls, babies—and girls in particular—may frequently be abandoned. It is essential that TASH members are aware that while numerous international standards exist to protect the rights of children confined in penal or correctional institutions and settings, there are no comparable international standards to protect the rights of abandoned or orphaned children.

An Opportunity

On September 30, 1990 the World Summit for Children galvanized a worldwide commitment to children. On that day, 71 Heads of State or Government signed the World Declaration and Plan of Action, committing themselves to achieving an agreed set of time-bound goals and mobilizing the human and economic resources to do so. The Declaration and Plan of Action set forth a vision of a "first call" for children by establishing 7 major and 20 supporting goals that were considered achievable by the year 2000. Subsequently, 181 countries endorsed the World Declaration and the Plan of Action, 155 of which prepared national plans of action for children.

A Special Session of the U.N. General Assembly is scheduled to take place in September 2001. The Assembly's Special Session on Children will review implementation of the Plan of Action agreed to in 1990 at the World Summit and identify what needs to be done to accelerate future progress. It will also endorse renewed commitments to children beyond the year 2001.

UNICEF (United Nations Children's Fund) is the substantive Secretariat for the Special Session, and as such is assisting in realizing each of the aims of the summit, which include: preparing for the Special Session of the General assembly, assessing what has been achieved for children worldwide and identifying challenges and strategies for the future. UNICEF is to produce a report on emerging issues and prepare the Secretary- General's report to the Special Session. UNICEF is to invite the participation of concerned parties, governments, UN agencies, non-governmental and civil society organizations, in the preparatory process of the Special Session. Bengt Lvinquist of Norway is the U.N. Special Rapporteur on disability issues who is charged with ensuring that the issues of children with disabilities are adequately addressed.

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The TASH International Issues Committee presented the following six-point agenda for inclusive disability policy/development for the CRC to the TASH Board in Miami in December 2000.

Six Point Agenda for Inclusive Disability Policy Development for the CRC

	Needed Policy Goals	**What it Would Mean to Achieve this Goal**
1.	Establish inclusive values, rights, and approaches for healthy child development	All children must be valued equally in law, public policy and practice - regardless of disability, or genetics or other characteristics. The unique potential of all children must be developed.
2.	Make reduction of child and family poverty a priority	Labor markets, income support programs, workplaces, and family supports must be designed to ensure adequate household income and have the flexibility to provide needed care and nurturing for all children.
3.	Ensure needed child and family supports - at home and in the community	Supports must be provided in flexible ways that strengthen citizenship by ensuring responsiveness to both child and family needs.
4.	Foster inclusive communities	Community services including schools, health care, recreation, and social services must be universally designed and operate inclusively.
4.	Strengthen civil society and build solidarity.	Decision-making in public organizations, agencies, schools, hospitals, government bodies must be democratized to include diverse family perspectives. Family organizations must be strengthened, and their participation in policy development supported.
6.	Commit to information gathering on disability for inclusive policy development	Population surveys, needs identification, and policy development must incorporate a "disability lens" to bring focus to the issues and needs of children and families.

Rationale for the Six Point Agenda for Inclusive Disability Policy Development for the CRC

◦ The CRC has been the guiding path for many policies and programs for children in the past ten years. However, under scrutiny, Article 23 by itself, does not sufficiently address the issues of children with disabilities nor does it serve sufficient incentive to ensure governments and the UN will adequately address the complex the issues of children with disabilities.

◦ In order to ensure that the rights of children with disabilities are highlighted and the issues are addressed, disability advocacy organizations must provide meaningful input to the process of the Special Session.

◦ The monitoring period for the U.N. Standard Rules has been extended to allow for further impact on governments and national policies; and The Special Rapporteur has been asked to pay special attention to the issues of children with disabilities as the Rules did not cover their issues adequately. The Panel of Experts may be reconvened to provide direction and Inclusion International must be clear on the TASH position on the rights of children.

◦ The themes "ready to learn," "healthy child development," and "prevention" are becoming increasingly prevalent in policy discussions. There is inherent danger that the interests of children with disabilities will not be adequately addressed if these terms are not tied to disability issues and concerns.

◦ The UN Human Rights Commission has appointed a Working Group to study the impact of the Convention on children with disabilities around the world. Reports are due before the special session, and input will be directed through Mr. Lindqvist to the U.N. Inclusion International is represented on the Working Group, and TASH needs to consider avenues to provide meaningful input.

Think globally, act locally While the Convention on the Rights of the Child is addressed to governments as representatives of the people, implementation is actually the responsibility of all members of society. CRC standards can be realized only when respected by everyone, including parents and members of the family and the community, as well as people working in schools, in other public and private institutions, in services for children, in the courts and at all levels of government administration. How will we, as TASH members, and TASH as an organization respond?

Anne Smith and Zuhy Sayeed are Co-chairs of the TASH International Issues Committee. Questions about the Convention on the Rights of the Child, or other areas of the committee's work may be addressed to Dr. Anne Smith by e-mail at <drannes@earthlink.net>

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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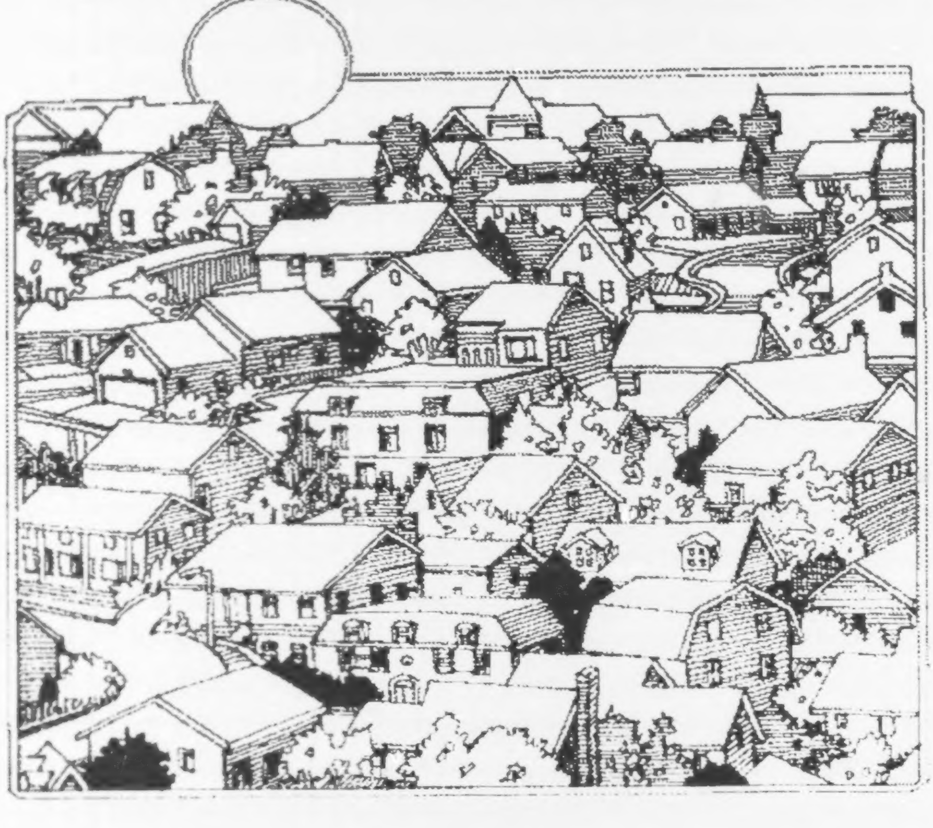
TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- Can Good Supports Happen in Bad Places?
- Unlocking a Universe of Opportunities in Housing
- Expanding our Thinking on Housing Choice
- Accessible Homes Mean Barrier-Free Friendships
- Advancing Affordable, Accessible, and Integrated Housing for All Americans

Increasing Homeownership Opportunities for People with Disabilities



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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

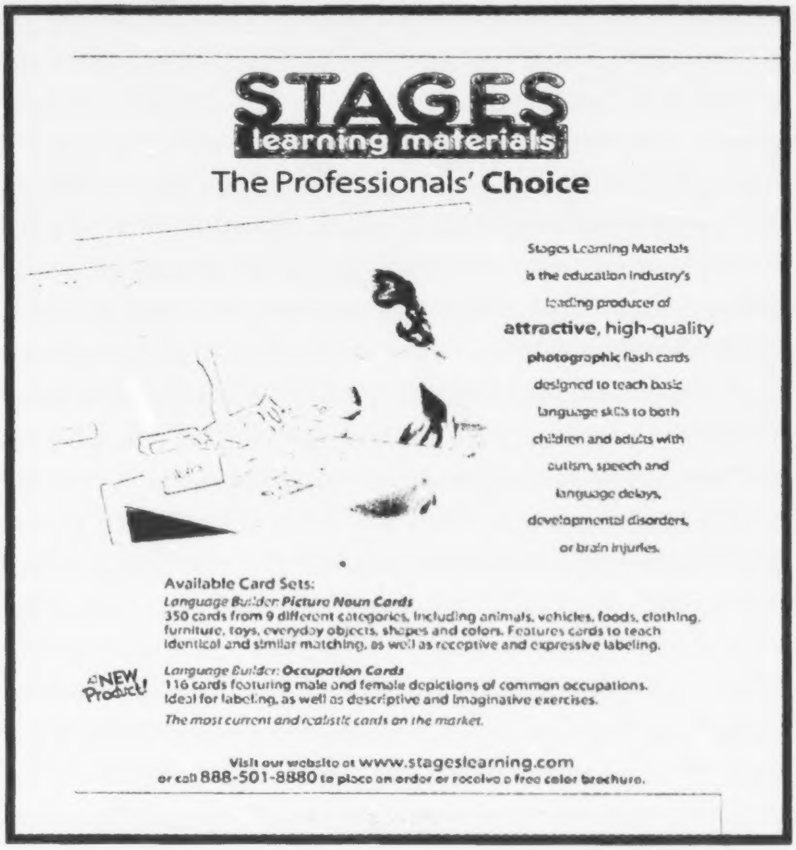
Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.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- ☐ **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- ☐ **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- ☐ **For questions about the 2001 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- ☐ **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- ☐ **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
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- ☐ **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- ☐ **Don't forget to visit TASH's web site at http://www.tash.org**

TASH Connections is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in TASH Connections should be sent to: TASH Connections, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Connections Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

From the Executive Director
BY NANCY WEISS

Can good supports happen in bad places?

This month's issue of TASH Connections focuses on housing but as the articles convey, where one lives is only part of what makes for a good life. It's how one lives that makes the difference for all of us. Choosing where and how one lives and having access to a self-directed, flexible array of supports is the combination that results in a life of quality and meaning for most people.

I often receive calls from people who work in segregated schools, institutions, group homes, or sheltered workshops. The callers want to know more about TASH. Almost without exception when I tell them that TASH supports the full inclusion of people with disabilities in general education classrooms, in their communities, and at work, the caller assures me that the place at which he/she works adheres to these same principles.

A recent exchange of this kind got me thinking, so I spent a little time on the internet ... it seems that TASH's values -- full inclusion and self determination are nothing new anymore. A private institution, in New Jersey, well known for the restrictiveness of its approach, describes itself on its web site as "family oriented and community-based." A state institution in Virginia describes its mission as supporting people with disabilities "so they can access a wide range of life's possibilities by fostering independence, self-esteem, and the fullest participation in family and community life." Voice of the Retarded, the only national organization that fights for institutions to stay open, says that it is their mission to focus on "quality of life and choice" and that they support "the right to live where [people with disabilities] feel comfortable, safe, and happy". Even the Judge Rotenberg Center, an institution in Massachusetts notorious for its indiscriminate and inhumane use of electric shock and other aversive procedures to change people's behavior, says that they "use behavioral procedures that rely on positive-only approaches" and that their goal is to "impart the skills each individual needs in order to live a happy, normal and productive life." Could it be that everybody is doing it? Could it be that an organization like TASH no longer needed because progressive supports have become status quo?

The readers of this publication will surely agree that there is still much work to be done before quality progressive supports are accessible to even a fraction of people with severe disabilities across the country.

I used to speak to groups about positive behavioral supports fairly often. The concept behind positive behavioral supports is that people act in ways that are challenging because they are frustrated by their life circumstances - by the lack of impact they are able to have, by being expected to perform meaningless activities, or by their inability to have their needs met in other ways. Often, when I would speak, people who worked in institutions or day wasting programs would ask me how they could implement the principles of positive behavioral supports in the environments in which they worked. I would tell them, you can't. You can wrap it up pretty, you can put whatever words make you feel better on your web site, but you can't provide good supports in bad places.

I recently received a phone call from a woman who told me that she worked in a twelve-bed group home for men with cognitive disabilities. "We want to implement a program of consumer-directed services" she told me, "but there's this one guy here who is very difficult. He won't eat at mealtimes, he insists on doing everything his own way, and basically, he refuses to go along with the program. What would you recommend I do?" she asked. I wanted to be helpful, I wanted to be diplomatic, but I couldn't think of any other response. "Close it down," I told her. We then went on to have a long talk (which hopefully was more helpful then my initial response) about why a person who lives with eleven other men, whom he had not chosen to live with, might be rebelling against the regimentation that such a life requires and why there is no way for self-directed supports to be compatible with this kind of environment.

In evaluating the quality of community supports there are many questions one could ask. Many checklists exist. I have found that there are only a few questions that are meaningful. When I am asked to assess the supports being provided in a living situation, I meet with the people who are receiving the supports and when appropriate, with their family members. I ask the people receiving supports, "Whose place is this?" You'd be surprised at how often people say, "the staff's," "the agency's," or "my parents'." I like to find out who has a key to the house or apartment. You'd be surprised at how often five or six different people have keys - everybody but the person or people who live there. Then I want to know from the person receiving supports and from their family members what they would make different if they could. Never in my years of asking has anybody said that he/she would like a fancier place or to move to a better part of town. When you ask people what they would change, answers revolve around the right to be in charge; to be the one who makes plans;

Continued on page 20

TASH: Public Policy in Action

THEY'VE GOT THE POWER in Madison, Wisconsin!

Three weeks after 3,000 advocates, many with disabilities, packed the Wisconsin State Capital demanding an end to waiting lists for community-based services, a legislative panel has approved a $19 million package to do just that. According to the Madison, Wisconsin Capital Times, the plan approved by the Joint Legislative Council last week uses federal Medicaid funds to address the shortfall in services to people who have developmental disabilities and their families.

Over the next two years, the plan would dedicate $3.5 million to the Family Support Program in Wisconsin, thereby reducing the waiting list by two-thirds. The Family Support Program funds flexible services for people with developmental disabilities who live with their parents or other family members. The Community Integration Program, which provides community-based alternatives to institutions, would receive $7.4 million over the next two years. An additional $8 million is planned for getting rid of all waiting lists for services over the same time period. Money would also be added for respite care.

The plan is expected to pass the full legislature because it would not rely on Wisconsin State funds and because it frees up funds for other social service programs. It also would help the State avoid legal action related to the 1999 U.S. Supreme Court Olmstead decision, which ruled that services for people with developmental disabilities and mental illness must be provided in the least restrictive setting appropriate for their needs.

The Wisconsin Developmental Disabilities Council estimates that 15,000 seniors and people with disabilities are on waiting lists for services in the state.

If folks in Wisconsin could organize and pressure their legislature, so can TASH members and allies in their own states!

This story was contributed by Dave Reynolds, Editor, Inclusion Daily Express, <www.InclusionDaily.com>

* * *

NEW PROTECTIONS FOR CHILDREN IN PSYCHIATRIC RESIDENTIAL TREATMENT CENTERS

Health and Human Services (HHS) Secretary Tommy G. Thompson announced new protections that will go into effect May 22, 2001.

The Health Care Financing Administration (HCFA) is issuing an interim final rule that establishes new standards for the use of restraints and seclusion that must be met by psychiatric residential treatment facilities that provide Medicaid's in-patient psychiatric benefit for individuals under age 21.

These requirements give essential guidance to psychiatric residential treatment facilities, which are rapidly replacing hospitals as a less restrictive treatment alternative for children and adolescents with psychiatric disorders. The rule further provides additional protections by adding a new requirement that these facilities inform HCFA of any deaths involving restraints or seclusion.

In addition, HHS is developing a rule that will set similar standards that will apply to children in certain non-medical, community-based facilities for children and youth as required by the Children's Health Act that was enacted by Congress in 2000. HCFA regulations currently include standards for use of restraints and/or seclusion in Medicare and Medicaid funded placements in hospitals, nursing homes and intermediate care facilities for people with developmental disabilities.

"This action will help protect vulnerable young people in certain Medicaid facilities from the risks of serious injury and death that are caused by the inappropriate use of restraints," Secretary Thompson said. "By developing a broader regulation covering other kinds of facilities, we will reach more children who need this type of protection."

The interim final rule amends a January 18 regulation, clarifying which facilities must comply with these requirements and what constitutes a restraint. The amended rule uses language to define a restraint that is consistent with the Children's Health Act.

The amended rule also requires any use of seclusion or restraint in a covered Medicaid psychiatric facility to be performed only on the order of and under the supervision of a physician, a registered nurse or other licensed practitioner permitted by the state to issue such orders, and who has been trained in the use of emergency safety interventions. These requirements, which are consistent with the Children's Health Act, ensure that restraint and seclusion will be conducted only by properly trained personnel while accommodating the staffing challenges that facilities face today.

This interim final rule will be published in the May 22 Federal Register and will

Continued on page 5

TASH: Public Policy in Action

Continued from page 4

be effective immediately. Comments on the amended language are encouraged and will be considered by HCFA. Additional details may be found at the following web address <www.hhs.gov/news>

* * *

The Office of Special Education Programs, Office of Special Education and Rehabilitative Services, U.S. Department of Education (OSEP) held their 2001 Leadership Meeting April 25-27. More than a day was devoted to presentations and discussion about the monitoring of the states' implementation of IDEA 97.

WHAT CHAPTERS AND MEMBERS NEED TO KNOW

Ten states have completed their Self-Assessments and will be monitored during 2001 and 2002. They are: Alabama, California, Indiana, Nevada, Kentucky, North Carolina, Oklahoma, Oregon, Rhode Island and Tennessee. Under OSEP's plan, states are currently engaged in a Continuous Improvement Monitoring scheme that requires state and local school divisions, state advisory committees and other "stakeholder" entities to engage in self-assessment that measures their success in fulfilling key Part B and Part C requirements under IDEA 97.

For example, one of the indicators to be used in Early Childhood Transition self-assessment activities would be "trained individuals, including parents, provide transition planning." School communities are then required to ask a series of questions about Early Childhood Transition and review the availability of data to support their assessment of how well they are doing in meeting the needs of young children and families is this area. The bottom line is supposed to be a fairly accurate set of data that reveals strengths and weaknesses and keys in on areas to be improved.

The Office of Special Education Programs will be using the Self-Assessments to formulate what they are calling a "Risk Factor Data Chart" that will guide not only what areas of concern will be monitored in each state, but also the level of federal involvement in each of those areas. A good example of a minimum level of OSEP involvement would be simply asking for additional data from a state. A high level of OSEP involvement would be a site visit for the purpose of holding public hearings and reviewing specific policies and programs. In all cases, OSEP will be using a partnering model for on-site visits whereby state folks will accompany federal site team members so they can see and hear the same things.

From this process will come an Improvement Plan, Implementation of Improvement Plan, activities designed to verify the effectiveness of the Improvement Plan and then a move back into the Self-Assessment. . .on and on. That's the "continuous" part.

OSEP has encouraged states to welcome and utilize a high level of family and community involvement. Chapter leaders and interested members can play a critical role in ensuring that toddlers, children and youth with significant service/supports needs are not overlooked as local and state school officials review their programs in preparation for federal monitoring. Areas of particular concern would include:

❖Teachers and related service providers who meet high professional standards in their training and their experiences (The requirement is for a Comprehensive Personnel Development system. It means just what you think it means -- looking for examples of best practices, bringing it to the districts, training the personnel and implementing best practice as well as monitoring the preservice training of teachers and related service providers. How's that working in your state?)

❖Services provided in high quality, age-appropriate and inclusive settings (What are your state's policies with regard to inclusive education for all children? Do these policies enhance or pose barriers for children and youth? Are students giving up instruction and support services to be included?)

❖Active educational programming (To what degree are students with significant needs receiving quality instruction? Active, age-appropriate access to the richness of the whole school curriculum and activities? Too much time at the supermarket learning functional skills?)

❖Accountability for "our" youngsters' achieving positive educational outcomes. (How do your school districts know that they are achieving positive outcomes for children, youth and families? Are they sincerely attempting to shift from paper compliance with IDEA to emphasizing positive outcomes? What procedures has your state developed to ensure that ALL students are making progress?)

Action steps for interested TASH members should include obtaining copies of State Self-Assessment documents and participating in opportunities for public input and comment. In addition, TASH members should know that OSEP will also be reviewing a state's "history" with regard to complaints, due process, previous areas of non-compliance and other factors that would render states "at risk" of non-compliance.

The TASH Government Relations office has state-specific information with regard to "risk factors" and other information.

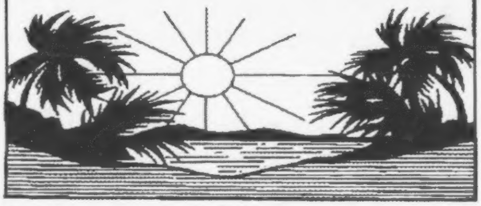
Contact Jamie Ruppmann for this, or any other questions you may have regarding Federal monitoring of IDEA, or any of the other information contained in this article. Jamie may be reached by e-mail at jruppmann@tash.org or by telephone at (410) 828-8274, ext. 104.

Plans for the 2001 Conference are really coming together! We have already received over 300 requests to present at this year's conference. Presenters will receive letters by the end of June indicating the status of proposals submitted. This year we will feature over 30 focus areas. Formerly known as strands, these focus areas will feature both one and two-hour sessions that were especially selected for their practical content and cutting edge information. Look for more structure and details on the following focus areas in the July Conference edition of TASH Connections:

Advocacy ~ Alternate Assessment ~ Autism ~ Critical Ethical Issues ~ Creative Arts ~ Community Living ~ Critical Pedagogy ~ Early Intervention ~ Employment ~ Euthanasia ~ Family ~ Friendship ~ Governmental Affairs ~ Guardianship Alternatives ~ Inclusive Education ~ Literacy ~ Media and Images ~ Post-Secondary Education ~ Multicultural ~ Paraeducators ~ Personnel Preparation ~ Positive Approaches ~ Related Services ~ Research ~ Self Determination ~ Sexuality ~ Spirituality ~ Teacher Preparation ~ Transition ~ Urban Education

“Imaging the Future”
2001 TASH Conference

Anaheim, California
November 16-17, 2001



Returning
Favorites

Back by popular demand is the Roundtable Luncheon and the Saturday morning Poster Sessions and breakfast. During the Thursday Roundtable lunch, join friends and colleagues from around the world as you enjoy great fare and stimulating conversation. Be sure to sign up for this event when you register for the conference — it is a great networking opportunity. If you are interested in facilitating a roundtable discussion, or presenting a Saturday morning poster session, there is still time to submit a proposal. Contact Kelly Nelson at TASH at <knelson@tash.org> or 1-800-482-8274 x105.

General Session Speakers

We are thrilled to announce the following slate of remarkable speakers during the general sessions. Here is a glimpse of their powerful messages:

Daniel Keplinger, about whom the Academy Award winning film, King Gimp, and the stunning and powerful advertisement released during the 2001 Super Bowl by Cingular were made. Throughout his life, in words and actions, Dan has embodied the values of TASH. We are pleased that he will be joining us in Anaheim, helping to shape an incredibly powerful dialogue about the role of media and advertising in changing the images of people with disabilities.

Tari Susan Hartman is President of EIN SOF Communications, a marketing, public relations, and production company based in California. Tari Susan has worked extensively on creating media opportunities for individuals with disabilities and has most recently promoted Nickelodeon's "Pelswick," an animated series about a 13-year-old boy who uses a wheelchair and attends his neighborhood school, created by syndicated cartoonist John Callahan.

John T. Sanford, Esq., is Director of the Office of Recipient Rights, Michigan Department of Community Health. John is a rousing advocate who is all about inclusion. He will share his insight about the structure of society as it pertains to eliminating the injustices and obstacles that face culturally and linguistically diverse and underserved individuals and families.

Jennifer Sheehy is the Director of Business Partnerships and Public Affairs for the U.S. Department of Labor. Ms. Sheehy came to the Presidential Task Force on Employment of Adults with Disabilities from the National Organization on Disability where she served as Vice President and Director of its CEO Council, a group of CEOs of leading companies throughout America whose mission is to challenge attitudinal barriers in the workplace and increase employment opportunities for people with disabilities.

Caroline "Ann" Thomas is an internationally accomplished self-advocate who travels throughout the US and abroad consulting and speaking about issues relating to self-determination, self-advocacy, and systems change. Ann is the incoming President for People First in Ohio and is a member of many committees. Ann is proud to be on the Robert Wood Johnson's Self-Determination Grant Steering Committee for the State of Ohio.

Continued on page 7

"IMAGING THE FUTURE" *2001 TASH Conference*

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2001 TASH Conference Hotel Information

The conference hotel is the Anaheim Marriott, located at 700 West Convention Way, Anaheim, CA 92802, Phone: 1-714-750-8000, Fax: 1-714-750-9100, or Marriott Worldwide Reservations 1-800-228-9290.

This year for the first time you can make hotel reservations for the TASH Conference directly on the web using the following Group Codes:

- Single room code is CITCITA
- Double room code is CITCITAB
- Triple room code is CITCITAC
- Quad room code is CITCITAD

Be sure to mention that you are making reservations for the TASH Conference to take advantage of these reduced rates.

Single Room - $140.00 plus tax
Double Room - $160.00 plus tax
Additional Person $20.00

Please be advised that the above rates do not include current room tax, which is 15%. The block of rooms held for the TASH Conference is being held until October 14, 2001. When the block is full, or after October 14th, rooms will be available if space permits, however, they may be at a higher rate.

Official Conference Airlines

Southwest and **United** will be the official conference carriers this year. You can make reservations directly with the airlines, or through a travel agent. Please be sure to reference the applicable ID Code to receive travel discounts. Flying with Southwest or United also enables TASH to offer scholarships for family members and individuals with disabilities to attend future TASH Conferences, as we earn one round-trip ticket for every 40 attendees that fly on the official conference airlines.

Southwest Airlines is offering a 10% discount on most of its already low fares for air travel to and from the TASH Convention. You or your travel agent can call Southwest Airlines Group and Meetings Reservations at 1-800-433-5368 and reference TASH ID Code: R7304. Reservation sales agents are available from 8:00 a.m. - 5:00 p.m. Monday -Friday or 9:30 a.m.- 3:30 p.m. Saturday and Sunday in all time zones. You must make reservations five or more days prior to travel to take advantage of this offer.

United Airlines is offering a 5-15% discount on air travel to the TASH Convention. You or your travel agent can call United at 1-800-521-4041 to book a flight. You will receive a 5% discount off the lowest applicable discount fare, including First Class or a 10% discount off of full fare unrestricted coach fares purchased 7 days in advance of travel. An additional 5% discount will apply for tickets purchased at least 60 days in advance of the travel date. Discounts also apply to Shuttle by United and United Express. Please be sure to reference TASH Meeting ID Number 594XG. Reservation agents are available 7 days a week from 7:00 a.m. to 12:00 midnight EST.

Watch for a complete listing of events and sessions for the 2001 TASH Conference "Imaging the Future" in the next TASH *Connections.*

ROUNDTABLE LUNCHEON

Join others from around the world to network at the Roundtable Luncheon on Thursday, November 15th from 1:00-2:15 PM. Enjoy a delicious box lunch while sharing stimulating discussions on a topic that interests you.

Tables will be marked with suggested topics for discussion and/or questions to stimulate thought. If you have a specific topic that you would like to discuss during lunch, please fax the following information, or include with your registration form when you mail it in.

I would like to participate in a discussion on:____________________

☐I am willing to facilitate this discussion.

☐I suggest the following person to facilitate this discussion

____

Participation in this event is only $20.00, which includes a delicious box lunch. Be sure to register when you complete your conference registration form.

Questions? Contact Kelly Nelson at 410-828-8274 x 105 or email knelson@tash.org. You can email your topic suggestions; fax them to 410-828-6706; or send a copy of this ad with your registration form!

TASH TECH Pre-Conference, Full-Day Workshops

Wednesday, November 14, 2001
1:00 - 6:00 p.m.

TASH TECHs are 5-hour, pre-conference workshops. There is an additional fee for attendance to these workshops, and pre-registration is required to guarantee seating.

T-1 If Everyone Agrees This IS SO Important, Why DO SO Few Kids Have Friends?

Facilitated by Carol Tashie and Zach Rossetti

Most people agree - friendship and relationships truly do make the world go 'round! However, many parents of children with disabilities report that their sons and daughters are lonely and lack meaningful relationships with classmates and friends. This workshop is designed to identify some of the real barriers to friendship and spark discussion on the strategies to support meaningful relationships for all children and youth. Through the use of the video "Voices of Friendship" the participants will learn about the relationship of five teenage girls and the lessons they have taught us on how to facilitate real friendships.

T-2 Using Internet Tools to Enhance Collaboration and Provide Training and Technical Assistance to Service Providers and Families: A Hands-on Demonstration

Facilitated by Richard Kiefer-O'Donnell

This workshop will demonstrate and train participants in how to use video conferencing, threaded discussions, chats, application and file sharing, whiteboards, and online broadcasts (webcasts) for team collaboration and provision of technical assistance at a distance.

T-3 Changes in Latitude, Change in Attitude: The Essential Role of Inclusion Facilitator in Promoting Full Inclusion

Facilitated by Cheryl Jorgensen

For schools to become inclusive, the role and title of special education teacher must change to that of Inclusion Facilitator. This full day workshop will present examples of the beliefs and skills necessary for supporting school communities to embrace inclusion.

T-4 Designing and Implementing Inclusive Curriculum: Teaching, Community and Standards

Facilitated by Mara Sapon-Shevin, Mary Fisher, and Paula Kluth

This interactive workshop will address strategies for designing and implementing inclusive curriculum for heterogeneous learners. Ways of incorporating state standard and IEP objectives within rich, cooperative, multi-level curriculum will be explored and experienced by workshop participants.

T-5 Literature-Based Language Intervention for Students Who Use AAC

Facilitated by Amy Staples and Beth Foley

This session will provide participants with current research findings regarding language and literacy development for AAC users, a framework for implementing literacy instruction, and an array of strategies for promoting interaction during literacy-based activities for elementary through high school students.

T-6 Partners in Justice

Facilitated by Debbie Gilmer, Diane Nelson-Bryen, Helen Bailey, Alan Hammond, Alan Kurtz, and Kathy Son

Every day people with mental retardation come face to face with the criminal justice system - as victims of crime, witnesses to crimes and as people accused of crimes. In this interactive workshop for criminal justice personnel, attorneys, advocates and others, the Maine Partners in Justice team will share strategies for getting relevant training to the front lines. Participants will receive a CD with the Maine version of the curricula.

T-7 Creating Inclusive Childcare Settings

Facilitated by Pam Miller and Peggy Fiore

This workshop will provide information on facilitating the collaboration of families, childcare professionals and other education and service agencies to successfully include children of all abilities in community settings. A variety of strategies offered by certified Project ACT teachers designed to educate child care providers, Head Start teachers, and public school teachers, as well as parents, the community, and other professionals will be presented.

T- 8 Creating Successful Experience for All Students Through Positive Behavioral Supports

Facilitated by Deborah Heeden, Barb Ayres, and Susan DeLuke

This interactive workshop will provide participants with information on positive behavioral supports. Key components that will be explored include: understanding your own attitude or posture; acknowledging the function of behaviors; gathering information about the student; and determining how difficult behaviors can be prevented. Participants will create social stories, visual schedules, and visual timekeepers that can be sued with the in individuals they support.

T-9 Exploring the Role of Spirituality and Disability

Facilitated by Kathy O'Connell, Bonnie Shoultz, Maureen Keyes, and Ron Taylor

This interactive workshop will explore various components of how spirituality can be an influential part of life for people living with disabilities. Specifically, this session will explore disability as a spiritual process, the power of meditation, imaging the future and spiritually centered leadership.

T-10 Civics 101

Facilitated by Marcie Roth and Jamie Ruppmann

This critical session explores how every one of us can achieve active, powerful participation in the democratic process. An overview of how government works and the places where activists can have the greatest impact on influencing social policy will be discussed.

T-11 Supported Living: It's not a program...It's your life!

Facilitated by Scott Shepard, Cheryl Mayfield, Keenan Inouye, Jose Perez, Pam Aiona, Carlos Cueva, Jill Martin, Igor Veremeykin, Ronda Michaelson, and Andre Vargas

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TASH TECH Pre-Conference, Full-Day Workshops

Continued from page 8

A panel of people who receive services and support staff will share their stories about what supports they need and how those supports need to be provided to keep people safe and active in their communities. A brief overview of what Supported Living Services can and should provide will be discussed.

T-12 Creating and Sustaining Positive Partnerships with Paraeducators

Facilitated by Deborah Tweit-Hull, Ann Halvorsen, Pamela Villalobos, and Dona Meinders

Paraeducators play a pivotal role in many inclusive classrooms, yet there are few opportunities for professional development or training. This interactive workshop will present strategies and share materials developed to train, mentor, and evaluate paraeducators to provide effective supports in inclusive classrooms.

T-13 Perceptions of Spanish Speaking Families Regarding Inclusive Education in Southern California

Facilitated by Mary Falvey and Ben Adams

This workshop - to be presented in Spanish with interpreters - will present the views and perceptions of Spanish speaking families as they share their experiences with inclusive education in South-Central Los Angeles. Participants will look at the meanings and beliefs that led them to make the decision to educate their children, who have severe disabilities, in the general education classroom. Strategies in collaboration and problem solving will be shared.

T-14 Transition as it Related to the Young Person with a Disability

Facilitated by Marilyn Barraza and Clare Miller

This workshop is designed to provide you with an awareness of transition as it relates to the young person with a disability and of the opportunities that these life changes can provide. Participants will engage in an exercise that enables them to identify the important values related to the decisions to be faced about the future and how values might impact decisions. Finally, each participant will draft a personal definition of what a quality life might look like, the first step in planning for the future.

At the request of our members, TASH is trying something new this year. Institutes are full-day, interactive workshops that are available to conference attendees who register for the full three-day conference at no additional charge. Others are welcome to register and attend a full-day Institute as an "Institute Only" registration at the rate listed on the registration form on page 10.

Full Day Institutes

Saturday, November 17, 2001
10:00 a.m. - 4:00 p.m.

I-1 Critical Pedagogy and Inclusion: Understanding Our World in Order to Change It

Facilitated by Jacqueline Thousand and Don Cardinal

Critical pedagogy explores the ways in which change is made in people's lives (all of our lives!). These ways don't necessarily fit with traditional parent/child, caregiver/service recipient, or teacher/student models of services. This session will encourage participants to challenge traditional ways of thinking about their roles as people with disabilities, staff members, parents, teachers, behavioral specialists, or other professionals and will encourage participants to rethink some of the most basic assumptions that have guided the field. Critical pedagogy suggest new ways of thinking and acting that will result in greater opportunities for mutually respectful relationships and social justice. Through dialogue we will address two questions. (1) How does understanding our world create the possibility of changing our experiences of the world we live in?
(2) What do we need to understand about our world in order to change it? Join us for this exciting, interactive day.

I-2 Families Planning Together

Facilitated by Shelley Dumas, Mary Lou Bourne, Amanda George, and Sherrie Anderson

In this full day institute, families will learn a step by step process for beginning development of an "essential lifestyle plan" with their family members as well as to identify methods of obtaining on-going planning assistance. The plans created during this full day workshop will be used to help ensure the presence in life of what's important to and for family members.

I-3 Implementing Social Coaching

Facilitated by Paul Selby

Across the country, many individuals with significant support needs are now living and working in the "community". Yet, too often, their supports are provided following the old segregation policies and procedures. This full day institute will present strategies for social coaching in the community.

I-4 Cultural Brokering: Application of a Model to Provide Supports to Individuals and Families from Diverse Communities

Facilitated by Paula Sotnik

For a recent immigrant with disabilities, the challenge of obtaining supports is often arduous. The Cultural Brokering Model provides service providers with a replicable framework to develop effective support strategies by examine all factors in a sequential and participatory manner. Participants will apply the Cultural Brokering Model to analyze and better serve individuals with disabilities and families from diverse ethnic, linguistic and cultural backgrounds using presentation, small group and case study analysis application.

I-5 Supporting Students with Autism in General Education Classrooms: Lessons Learned

Facilitated by Michael McSheehan and Rae Sonnenmeier

Learn about New Hampshire's statewide system change efforts to support students with autism in general education classrooms. Examine the content covered in the varied training activities and the process for facilitating and sustaining change. Participate in skill building activities for professional and leadership development.

I-6 Stepping Out: A Game of Life that Goes to the Heart of What it Means to be Human

Facilitated by Sally Sehmsdorf, Chris Bily, Erin Bily, and Sherry Lookabill

Stepping Out explores the Art of Dialogue, Person Centered Planning, and Diversity. Participants with and without disabilities collaborate to construct a game and play it. Imagine a giant board game with a path that begins with dreaming, moves through confusion to reflection, creates a space for calling a circle of friends, and finally reaches its goal of contribution to the community and full inclusion.

Continued on page 24

TASH

Conference Registration

(Esto forma es disponible en español)

INTERNET
TASH Office Use Only
Org ____________ **Cust** ____________
Reg ____________ **Init** ____________

Instructions for filling out this form:

1. **Pleases print and fax or send this form.**
2. **Fill out one form for each person attending**
3. **A form of payment must accompany your registration Please make checks payable to TASH.**

TASH Federal Id # 51-0160220

Mail: TASH, 29 W. Susquehanna Avenue,
Suite 210, Baltimore MD 21204
Fax: (410) 828-6706
Questions? 1-800-482-TASH (8274) or 410-828-8274;
TDD: (410) 828-1306
Email: registration@tash.org
Website: www.tash.org

Conference Participant:

First Name: ____________ Last Name : ____________ Badge Name: ____________
Organization: ____________ Address: ____________ City / State: ____________
Postal Code: ____________ Country ____________ This address is [ ] home [ ] work [ ] school [ ] other ____________
Work Phone: ____________ Home Phone: ____________
Fax: ____________ E mail: ____________

♿ Accommodations needed:

	Registration Category – Current TASH International Members		
[ ]	Individual Registrant	**$239**	Current TASH Member # ____________ (**Personal assistants must register at the same time as individual for whom they are providing support to attend conference activities*)
[ ]	Family Member / Or Person with a Disability	**$ 79**	
[ ]	Personal Assistant *	**$ 50**	
[ ]	Student	**$ 159**	
[ ]	One day only ☐Thurs ☐ Fri	**$149**	

	Registration Category – TASH Chapter Only or Non-Members		**Register and JOIN International TASH NOW!!**
[ ]	Individual Registrant	**$369**	**$327**
[ ]	Family Member/ Or Person with a Disability	**$155**	**$124**
[ ]	Personal Assistant (**see note above*)	**$50**	**$95**
[ ]	Student	**$259**	**$204**
[ ]	One day only ☐Thurs ☐ Fri	**$199**	**$237**
	1. Enter Registration Cost		**To join your chapter also please add $15.00** $ ____________

Additional Registration Discounts		
A. Team Discounts - Groups of 5 or more registering together **(must be in the same envelope)** **B. Early Bird -** registrations received before Sept. 1, 2001	**Subtract Discount Here →** $20.00 per person, per discount	$ -____________
Round Table Networking Luncheon – Thursday, 1:00-2:15 PM *(you must purchase a ticket in advance, and please be sure to note any special diet requests)*	$20.00 per person **Add Luncheon Fee Here →**	$ ____________

Pre-Conference Workshops 1:00 - 6:00 PM, Wednesday, November 14th (*Registration is in addition to the conference fees*)
Saturday Institutes, 10:00 AM - 4:00 PM November 17th (If you registered for the Full conference you can attend one of the Saturday Institutes at no charge. If you would like to sign up to attend an Institute ONLY - the rates below apply.

Please review the TASH TECH Workshops and Institute descriptions on pages 8-9. Be sure to mark the number of your first and second choices.

○ I plan to attend the TASH Chapter Leadership Day (no charge)
○ I plan to attend a TASH TECH 1st Choice _____ 2nd Choice _____
○ I plan to attend a Saturday Institute 1st Choice _____ 2nd Choice _____

Enter Total Additional Fee Here →

Rates for TECHS **and** Institutes:

TASH Member	$55.00
Non-Member	$85.00
Individual w/a disability or Family Member	$40.00

$ ____________

I would like to make a donation to support a self-advocate/parent $5___ $10___ $15___ $ ____________

Payment Terms: ○*Check* ○*Purchase Order* ○*Visa* ○*MasterCard* ○*Discover*

Name: ____________
Card # ____________ Exp. ______
Signature: ____________

TOTAL AMOUNT ENCLOSED $ ____________

Registration will not be accepted without payment by check, purchase order, or credit card authorization. Payment must be in U.S. Funds only. A $25.00 fee will be deducted from all requests for refunds received before October 15, 2001. No refunds after that date. $25.00 fee for returned checks or unauthorized charges.

TASH: The Action Starts Here ...

While it's true that the acronym TASH doesn't really stand for "The Action Starts Here," TASH members know that it is TASH's clarity of vision and willingness to take action that distinguishes us from many other groups.

Throughout our now 26-year history, TASH has led the way to assure that:

- the rights of people with disabilities are protected;
- progressive research is assured the support and audience it deserves; and,
- individual and legislative advocacy is available whenever needed.

We need your help to support and sustain the critically important work that TASH has begun. Please consider a contribution or a plan for giving that will secure the future of TASH's daily action toward progressive supports and inclusive lives for all people with disabilities.

Gifts may be made by check or credit card. All gifts -- regardless of the amount -- will be greatly appreciated. No amount is too small.

Do also consider:

- ***Contributions of stocks or securities***
- ***Remembering TASH through your will or living trust***
- ***Beneficiary designations of life insurance or pension plan proceeds***
- ***Gifts with retained income for you or others***

Charitable gifts are tax deductible. To discuss your options for making a donation to TASH, or to request a copy of TASH's Charitable Giving brochure, please contact Nancy Weiss at 410-828-8274, ext. 101.

Thank you for your assistance in securing the rights of all people to live and participate successfully in the community!

TASH's work is dependent on the financial support of our members. We wish to acknowledge the generous assistance of our newest lifetime member

Karen Zimbrich ~ Watertown, MA

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, please contact Rose Holsey at 410-828-8274, ext. 100.

* * *

Thanks, too, to the gracious donations of the following individuals:

Sally Ray Griffith
Teddi Leiden
Sara Pankaskie
Elisabet Van Swam

The University of Washington Graduate Program

trains teachers to serve the needs of pre-K through secondary pupils with significant disabilities. Emphasis on databased, systematic instruction referenced to the requirements of natural school and community settings.

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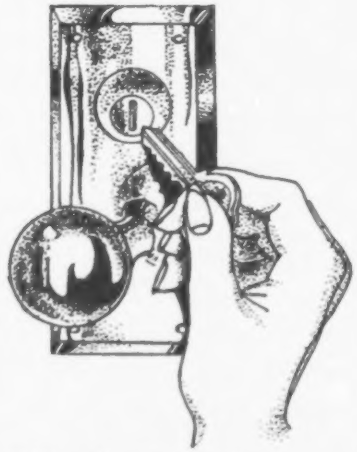

Unlocking a universe of opportunities in housing

BY BECCA VAUGHN

People with disabilities face many obstacles in their daily lives. In recent years, one of the central obstacles that the grassroots disability activist movement has focused on has been barriers to accessible, affordable and integrated housing. In 1994 the first national grassroots housing justice coalition, the Disability Rights Action Coalition for Housing (DRACH), was formed. Comprised of people with disabilities — many of whom lived in public housing — the coalition's primary purpose was to address discriminatory housing programs, most of which the U.S. Department of Housing and Urban Development (HUD) operated. While there were other groups that claimed to represent people with disabilities, DRACH was the first group to meet with the Housing and Urban Development (HUD) Secretary, delivering a passionate report of the struggles for real housing from the people HUD's oppressive policies and programs affected.

DRACH has six major national goals it works toward to end years of discrimination, segregation and isolation in housing for people with disabilities. They are:

- Ensuring stronger enforcement and full compliance with the civil rights housing laws
- Ending segregated housing for people with disabilities
- Eliminating the mandatory linkage of services from housing
- Increasing tenant-based rental assistance
- Developing homeownership opportunities
- Promoting on a national scale the "visitability" concept or basic accessible housing

DRACH has identified nationally the number one barrier to equal housing opportunity: a lack of understanding of and compliance with the fair housing laws. Many federal and state programs for too long have encouraged "mandatory service participation" (i.e. in order to have a roof over one's head, one must eat the meals provided or accept the case management offered) in blatant violation of the Fair Housing Act. Many builders are not in compliance with the accessibility requirements and much of the housing industry does not understand granting reasonable accommodations and, in fact, claims not to know anything about civil rights housing laws.

Did you know...?

⇨ All new construction of multi-family housing must contain 7 features of accessibility? (These features are listed later in this article.)

⇨ It is illegal for anyone renting or selling housing to ask if you have a disability, or to inquire into the nature or severity of your disability?

⇨ You have the right to a reasonable accommodation in any rule, practice, policy or procedure if the change will allow you equal access to and full use of a housing program?

⇨ You have the right to request reasonable modification to any and all housing if the modification will allow you full use and access into the home?

⇨ You have the right to be treated with respect and dignity and to access any home you want, free from discrimination?

Fair Housing Rights

What are the federal fair housing laws?

There are three major federal civil rights laws that provide protection from discrimination for people with disabilities in housing. Note that some laws only apply to housing that is subsized with funds from the federal government.

The following Federal civil rights laws prohibit discrimination against people with disabilities in housing:

1. **Fair Housing Amendments Act** (1988)
2. **Section 504 of the Rehabilitation Act of 1973** (this law applies only to federally funded projects)
3. **Americans with Disabilities Act** (1990) -- Titles II and III

Fair Housing Amendments Act

In 1988, the Fair Housing Act (Title VIII of the Civil Rights Act of 1968) was amended to expand protections against discriminatory housing acts to people with disabilities and families with children. This act is referred to as the Fair Housing Amendments Act

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Unlocking a universe of opportunities in housing

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(FHAA), and applies to all housing and housing-related activities, including the real estate industry, lending institutions and providers of homeowners insurance.

Protected Classes. Housing discrimination is prohibited on the basis of:

- Race or color
- National origin
- Religious preference
- Gender
- Familial status
- Disability

The general protections include such areas as:

⊙Refusal to rent, sell or negotiate for housing
⊙Falsely denying that housing is for sale or rent
⊙Making housing unavailable
⊙Providing different housing services or facilities
⊙Blockbusting (steering people of similar status away from or into certain neighborhoods or programs)
⊙Discriminatory property appraisals/ insurance denials
⊙Unfair mortgage lending/loan denials
⊙Setting different terms and conditions in sale or rental of a dwelling (i.e.: tenants with power chairs pay higher rents, or people with disabilities are required to receive meals provided)
⊙Imposing different selection criteria in housing applications (i.e. tenants with disabilities must be able to live independently)
⊙Advertising or making statements that indicate preference based on protected status.
⊙Threatening, coercing, intimidating or interfering with anyone exercising his/ her fair housing right. Retaliation is illegal!

Additional protections for people with disabilities include:

⊙ Prohibiting inquiries as to severity or nature of disability
⊙ Right to reasonable accommodations
⊙ Right to reasonable modifications
⊙ Accessibility requirements for new multifamily dwellings (4 or more units)

Except in very few situations, the Fair Housing Amendments Act applies to all housing, private or federally-funded (subsidized). People with disabilities carry with them their civil rights and fair housing protections in any housing situation.

Knowledge is power and knowing your rights will help others understand their responsibilities and their obligations to comply with those rights.

Exemptions from the FHAA. There are some exemptions to the Fair Housing Amendments Act. Among these are:

⊙ Single-family housing sold or rented without a broker
⊙ Owner occupied buildings with no more than 4 units
⊙ Housing operated by private clubs and organizations (i.e. those receiving no federal funds)
⊙ Some senior-only buildings exempt from familial status/age

The FHAA also contains new construction requirements for all multifamily dwellings built for occupancy after March 13, 1991. All units in a building with an elevator and all ground floor units must be built with 7 basic features of accessibility:

New Construction Requirements Under the Fair Housing Amendments Act for Multifamily Dwellings Built After March 1991

1. Accessible entrance on an accessible route
2. Accessible public and common use areas
3. Usable doors
4. Accessible routes into and through the dwelling units
5. Light switches, electrical outlets environmental controls accessibly located
6. Reinforced walls for grab bars
7. Usable kitchens and bathrooms

For example if you have been told things like, "we don't rent to disabled people," "it will cost you more in rent since you use a power wheelchair," or have been asked such questions as, "can you live independently," "what kind of disability do you have," how does that make you act," you have been denied your fair housing rights.

Let's say you want to rent a small, single family home in a neighborhood that you like because of the tall trees and quiet environment. You call to look at the home and when you get there (using your wheelchair) the broker says it's not accessible and denies your right to look at the home even if you are able to arrange a way to get in. You have been discriminated against. Another example would be if you request to build a ramp at the front door and the landlord/ manager says you can't build one. This is illegal and you have been discriminated against. It is important to note that with regard to private housing not funded with federal money, you will need to pay for any needed modification.

Knowledge is power and knowing your rights will help others understand their responsibilities to comply with those rights.

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Unlocking a universe of opportunities in housing

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Section 504 of the Rehabilitation Act of 1973

Section 504 covers all federally funded housing units, programs or projects. The law is very clear: when it says all, it means all, with no exceptions! Examples of federally funded programs are:

- Public Housing Authorities (PHAs)
- Section 8 housing programs
- Section 811 and 202 programs
- Programs serving homeless populations
- Shelter Plus Care
- Community Development Block Grant (CDBG) recipients and sub-recipients
- All Rural Housing (USDA) projects

Section 504 federally funded projects are prohibited from discriminating against any person with any type of disability, and are required to assure equal participation in the housing program.

Section 504 accessibility requires all units built or renovated to contain at least 5% fully wheelchair accessible units, 2% of the units must be accessible to individuals who are deaf or have hearing impairments, and 2% of the units must be accessible to individuals who are blind or have visual impairments. They are not to be the same unit. There must be at least one unit with accessibility features to accommodate each of these types of disabilities.

In addition, federally funded housing providers must pay for any reasonable accommodation or modification that is requested.

Section 504 requirements are in addition to those of the Federal Housing Amendments Act for federally funded programs.

Americans with Disabilities Act

Title III of the Americans with Disabilities Act (ADA) applies very narrowly to housing. The ADA does not cover individual housing units (these are covered by the Federal Housing Amendments Act and/or Section 504 if federally funded), and only affects public use areas and rental offices of multi-family projects.

For example, only the areas within an apartment complex which are open for public use must be accessible according to the Americans with Disabilities Accessibility Guidelines. This would apply to real estate offices, banks and other housing broker offices. Generally, the ADA applies to situations other than housing such as employment, public accommodations, transportation and communications.

◆◆◆◆

Reasonable accommodations are a major key to unlocking a universe of opportunities in housing and beyond. Getting the type of housing you want may require that you exercise your rights.

A person with a disability may request changes in any rule, policy, procedure or service if the changes are related to a disability, and are needed in order for the person to have equal access to housing, services, employment, stores, schools, or the community. Such changes in policies or services are usually referred to as reasonable accommodations.

A person with a disability may request that structural, or other physical changes be made in a building, apartment, or workplace, if such changes are related to a disability and are needed in order for that person to have equal access. Such structural changes are usually referred to as reasonable modifications.
It is important to remember that the individual must request whatever accommodations and modifications she or he needs. In most cases, the employer, school or business must pay for the accommodation or modification. In housing, only subsidized housing providers must pay for any modifications to apartments and common areas. Private housing providers need not pay for the modifications, but they must allow the tenant, at his or her own expense, to make the needed modifications.

The term "reasonable" does not mean "sensible" or "acceptable." "Reasonable" means that the action requested by the individual with a disability:

- ◆does not cause an undue financial burden;
- ◆does not cause a basic change in the nature of the program; and
- ◆is technologically possible

"Reasonable accommodation/modification" is a central tenet in all disability civil rights laws, not just in housing. The following sample procedure for requesting accommodations/modifications refers to a housing situation, but you can use the same procedure in employment, transportation or public accommodations if you need an accommodation.

Suggested Procedure for Requesting an Accommodation/Modification

Start by providing in writing the following information (examples are given following each item).

1. Indicate that you qualify as an individual with a disability as defined by the civil rights laws. Never reveal the nature or severity of your disability. **Example**: "*I qualify as an individual with a disability as defined by the Fair Housing Act.*"

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Unlocking a universe of opportunities in housing

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2. Describe the policy, rule, or service that is problematic for you. **Example**: *"Your housing program has a 'No Pets' policy."*

3. Briefly explain how the policy interferes with your needs/rights. **Example**: *"I depend on a service dog for assistance."*

4. In very clear language, fully describe the change you are seeking in the policy, rule or service. **Example**: *"I am requesting a change in your 'No Pet' policy so that my assistive animal may reside with me in the housing unit."*

5. Ask for a written response within a specific time period. **Example**: *"Please respond in writing within five working days."*

6. Always sign and date your request.

7. Either at the end of your request or on a separate sheet of paper provide a statement similar to the following, signed by an appropriate medical professional (doctor, therapist, counselor, physical therapist):

The accommodation requested above by my client/patient is consistent with his/her needs associated with his/her disability (ies). The medical professional should sign his/her name and print his/her name and title.

8. Always keep a copy of your request for your files.

9. If the request is denied, contact an advocate to determine if your rights have been violated. You may also want to consider filing a discrimination complaint with your local or state human rights commission, the Department of Housing and Urban Development (HUD), the Department of Justice or any other governmental body which may have jurisdiction over your area of complaint (employment, education, housing, etc.).

Retaliation is illegal! You cannot be evicted from your home because you are exercising your fair housing rights.

Fair Housing Complaints

If you believe your rights have been violated, you may want to file a fair housing complaint or file a lawsuit in a Federal or local court. You may also want to contact an advocate who can assist you with the complaint process. Information on filing complaints can be found on the Housing and Urban Development (HUD) website at: www.hud.gov, by calling DRACH at 1-800-443-2207, or by contacting your local/state human rights organization or other local advocacy groups. You may want to discuss possible mediation/advocacy efforts prior to filing a complaint.

Now that you have some important tools to help tear down the barriers to accessing affordable, accessible, integrated housing of your choice, let's briefly discuss some housing options for rental and homeownership.

Rental Options

You have the right to ask to look at and be shown any available rental housing. You have the right to modify any home, through a request for an accommodation.

Remember, a private property owner does not have to pay for any modification, but the owner cannot refuse a reasonable request for a modification to be made by a tenant with a disability.

Subsidized (Low Income) Housing

Section 8: What is it?

Section 8 is a federal housing program that gives low-income people access to decent, safe, sanitary, affordable, accessible and integrated housing choices. There are two types of Section 8 assistance. The first is a project-based voucher program (an existing building the housing provider owns and operates). The second is a tenant-based voucher program (the tenant finds his/her own home). Both programs are administered through public housing agencies, such as a housing authority or state housing finance corporation. You must be income eligible and apply through an agency which operates a Section 8 program. You can get a listing of such agencies from the HUD website <www.hud.gov>

Section 8 Tenant Based Vouchers have nationwide portability, so you can move anywhere you choose in the United States. The vouchers can be used to help pay a home loan. However, your local housing agency must be a participant in such a homeownership program. If they do not already have one, you can talk with your local agency and ask them to develop a program, or request to buy a home with your voucher as an accommodation.

It is important to note that private landlords who accept your rent payment under the Section 8 program do not have to pay for any modifications as they are not directly funded by the federal government.

There are also low income projects which are privately owned and operated and/or funded by HUD or rural housing authorities. The HUD website will provide listings of HUD funded programs and also provides a link to the Rural Housing site.

Your state or local government may also have housing assistance programs available which are funded with state or local funds. Contact your local/state community planning office or department of housing. (States/cities use different names for the office that deals with housing, so you may have to make several calls.)

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Unlocking a universe of opportunities in housing

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Access Modification Funding

Many states and local governments operate programs to assist low income people with disabilities in paying for necessary modifications to their homes. Ask about this option. Cities and states can use federal Community Development Block Grant and HOME funds for such programs. If your city or state doesn't offer such a program, ask them to establish one. Call DRACH for more information on this advocacy action.

Homeownership Options

You have the right to apply for a loan to purchase a house, the right to be shown potential homes, and the right to request reasonable accommodations in order to access/qualify for a home loan. Many states, banks and cities have First Time Homebuyer programs. Ask local housing lenders and city offices what type of programs are available.

Fannie Mae (1-800-732-6643) and the National Home of Your Own Alliance (1-800-220-8770) have many resources and helpful guides available. Additional housing advocacy resources are listed beginning on page 25 of this issue of TASH Connections.

Conclusion . . . and Beginning

Getting the home you want sometimes takes a willingness to defend your rights for accessible, affordable housing. Remember, you have the right to request an accommodation — even to banks or other lending institutions — if it will give you equal access into the program. An example would be if you have some negative or questionable items in your credit history which were directly caused by your disability (medical bills, equipment expense, lost wages due to injury). You can ask that the lending institution not consider that credit history when determining your eligibility. Provide them with alternative credit history that is positive such as utility bills or rent receipts that will document that you are financially responsible enough to own a home.

Demand that housing managers treat you with respect and dignity, extending to you the full fair housing rights to which you are entitled. If a manager asks about your disability, tell him/her it's none of his/her business, that it's private, and that asking violates the fair housing laws. You cannot be charged extra rent because you use adaptive equipment. You do not have to pay a pet deposit on any animal that provides you with emotional support or performs a service, as long as the need for that support is related to your disability. You have the right to ask for an accommodation in any rule, practice, policy or procedure if it will allow you to live in a home of your choice.

We must stop the practice of funding housing projects which segregate and isolate or dehumanize people with disabilities. No more mini-institutions, no more oppressive, disability-specific programs, no more "special needs" (i.e., different from everyone else) housing. It is time for our nation to stop the discrimination against, and the exclusion of millions of human beings from real housing opportunities solely because they have disabilities. We must stop viewing disability as a crime and work to assure equal rights and justice for all.

For additional information please contact DRACH:

Disability Rights Action Coalition for Housing
501 SW Jackson, Suite 100-B
Topeka, KS 66603
1-800-443-2207-toll free
1-785-233-0779-fax and voice
1-785-233-4572-voice and TTY
e-mail: DRACHQB@tilrc.org

South Coast ESD - Region #7

Teachers needed to work with children with significant disabilities.

Public schools on beautiful Oregon Coast have immediate openings for innovative, collaborative teachers with licensure and education/experience with students with significant disabilities.

Prefer skills in augmentative/alternative communication, behavioral analysis including communication functions, positive behavior intervention, supports for inclusion, functional assessment/instruction, curricular modification, and transdisciplinary service delivery.

Send resume along with letter of interest to:

South Coast ESD
1350 Teakwood
Coos Bay, Oregon 97420
Telephone: 541-269-4520
TDD: 541-269-1611
E-mail:
sharronw@mail.scesd.k12.or.us

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Expanding our Thinking on Housing Choice

BY CHARLENE DWYER
and
JERRY VOGT

In the disability community, we are used to appalling statistics. You know the kind, those depressing facts and figures that remind us that people with disabilities continue to live as second-class citizens. Housing statistics are among the worst.

Last year, the House Subcommittee on Housing and Community Concerns stated that while the overall homeownership rate is approximately 67% nationwide, the average homeownership rate for African-Americans is in the 40th percentile and Hispanics register, in some communities, as low as the 20th and 30th percentile.

But what about people with disabilities? The National Home of Your Own Alliance reports that less than 5% of people with disabilities who receive Social Security Income (SSI) benefits own their own homes.

There's more. . . A 1998 national Louis Harris poll commissioned by the National Organization on Disability found that 34% of people with disabilities have annual household incomes of $15,000 or less. Meanwhile, the Department of Housing and Urban Development (HUD) recently reported that rent prices increased more than twice the rate of national inflation in both 1997 and 1998. In 2001, HUD reported that their housing research identified very low-income households that included adults with disabilities as a segment of the population having some of the most significant housing needs of any group in the United States.

Not surprisingly, national housing advocacy groups also verify that lower-income families are being continually priced out of the nation's safe and affordable rental market. In "Priced Out in 1998," the CCD (Consortium for Citizens with Disabilities) Housing Task Force reported that there is not a single housing market in the United States where a person with a disability receiving SSI benefits can afford to rent a modest efficiency apartment, and nowhere can an SSI recipient rent a one-bedroom apartment for less than 50% of his or her income.

The housing crisis for people with disabilities is both alarming and escalating. But even amidst the most negative trends, there is good news. New and expanded opportunities in affordable, accessible housing choice are emerging. They range from a concerted effort by HUD to increase Section 8 vouchers targeted for people with disabilities and those who are home-and-community-based-waiver (HCBW) eligible, to home mortgage payment programs subsidized with vouchers. The scope is broad, but the focus is clearly on low-income people with significant disabilities. HUD makes the programs available; State and local public housing authorities and people with disabilities, their advocates, and their service organizations make them a reality - if they choose to do so.

These new initiatives hold great promise — not as the solution for everyone — but as an important part of a full range of housing choices. They expand community living options and foster integration of people with disabilities into their neighborhoods.

The Section 8 Housing Choice Voucher is available by application now!

The time to apply for a Section 8 "mainstream voucher" is now. HUD is making over $54 million for approximately 1,900 5-year housing choice vouchers available to public housing agencies (PHAs) and nonprofit disability organizations. With the vouchers covering as much as 70% of area fair market rent, people with low-incomes and with disabilities can afford a better quality of housing when they have a voucher in hand. Now is the best time to assure that a Section 8 housing choice voucher is available to every person with a disability in your community who needs one by applying for the mainstream vouchers. The application deadline is **July 20th**. Contact your State and/or local public housing authority to establish an application partnership. If you are a qualified non-profit, consider making an application on your own. For more information on how to apply for the vouchers, log on to http://www.hud.gov/adm/grants/nofa/grpsec8.html

Owning a home is about choosing where you live and having the opportunity to live on "a tree-lined main street of America." But the real strength of homeownership as a housing option is that it is not limited to that. Homeownership is also about more people with disabilities investing in their housing and capturing their fair share of the savings in U.S.- owned homes so that they can live in the "equity-lined main stream of America."

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Expanding our Thinking on Housing Choice

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The new Section 8 Housing Choice "Homeownership Option" Voucher

It's also a good time to aggressively expand both our thinking and efforts to include homeownership as a viable option in the spectrum of affordable, accessible housing choices. Why? Because not only can "purchasing" your housing rather than "renting it" expand choice and maximize control, but it also provides an avenue to improve and stabilize housing.

Homeownership also happens to be our nation's #1 vehicle for personal asset accumulation. Congress reports that there is more than $4.5 trillion in equity and savings in owned homes in the U.S. Using "subsidized housing" as a means to gain equity and build "personal assets" has never been a widespread option. Now it is.

OWN
YOUR
HOM

In its most simplified form, the brand new HUD Section 8 homeownership option allows a State or Local Housing Authority to create a "homebuyer" option for their housing choice voucher families. For a qualified homebuyer family under the new program, the monthly voucher subsidy, traditionally used for a rent payment, can be used instead towards a mortgage payment.

The same rental voucher that pays as much as 70% of area fair market rent for a user can now be sent to the bank to pay a portion of a monthly mortgage. Combined with other low-income homebuyer assistance programs such as discounted interest rates and downpayment grants and loans, the value of the monthly voucher will significantly increase the family's home purchasing power. The voucher is a new and important piece of the affordability puzzle for homebuyers.

But what about the lending institutions where high incomes, big down payments and low housing spending ratios are favored? Fortunately, some mortgage lenders are taking the time to learn how many with disabilities live -- with fixed and capped incomes, limited credit histories and cash assets and sometimes with their housing assets held in protected trusts. Some of these lenders are also beginning to accept how people with disabilities as a group prioritize their spending, putting more of their resources towards their housing than their non-disabled neighbors.

Mortgage products and underwriting flexibilities designed to accommodate families who rely on disability benefits as a main source of income are available through Fannie Mae's HomeChoice mortgage guarantee program. As a national leader in promoting homeownership among people with disabilities, Fannie Mae is finalizing its mortgage underwriting for the new Section 8 homeownership program.

Last year, HUD supplied all of their FHA lenders with guidance on providing underwriting flexibilities to accommodate persons with disabilities in qualifying for a mortgage. With leadership from HUD and Fannie Mae, lenders interested in providing market rate mortgages to low-income homebuyers with disabilities may not be far behind. There are lenders who are taking the time to get to know people with disabilities, and these same lenders are providing new access to mortgage credit.

State and local housing authorities can assist housing organizations to develop creative ways of using the new Section 8 homeownership option to advance home buying by people with disabilities. Housing authorities and their disability partners are making it happen across the country.

The Section 8 homeownership option is available and the pieces of the lending puzzle to support the program are falling into place. Great news! But the "opportunity" doesn't materialize into the "reality" of a home until a PHA (public housing agency) adopts the program and offers it, along with a Section 8 housing choice voucher, to income-eligible individuals with disabilities. There's no way around it, there's still a lot of infrastructure and partnership work to do.

Even with a brand new program and a long and steep learning curve, there are model Section 8 homeownership pioneers among us. Using HUD demonstration authority, the Colorado Department of Human Services Supportive Housing and Homeless Program (SHHP), a HUD authorized housing authority, implemented the homeownership option on a statewide basis for people with disabilities. SHHP has partnered with non-profit agencies connected to the disability community to provide local outreach and support to homebuyers. They have already used the program successfully to assist qualified Section 8 families in buying homes. Be sure to read the Section 8 homeownership "success stories" at the end of this article. As a willing and able pioneering housing authority, the Colorado SHHP earned a HUD national "Best of the Best Practices" award in 2000 for paving the way for the rest of us.

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Expanding our Thinking on Housing Choice

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In the State of Wisconsin non-profits like EBTIDE, Inc. and Movin' Out have focused their efforts on people with disabilities who live on low incomes. We have bolstered the homeownership rates by securing hundreds of thousands of dollars in downpayment grant assistance from the Federal Home Loan Bank of Chicago and distributing it throughout the state. In the City of Milwaukee, the Housing Authority is working collaboratively in both the planning and implementation phases with EBTIDE and IndependenceFirst, the local Center for Independent Living, to initiate their Section 8 homeownership program and make it inclusive of people with disabilities. Of course, the targeted downpayment grants will be a part of this new opportunity.

These housing authorities and their disability partners are making it happen. We can only hope that there are many more examples of state and local housing authorities using the new Section 8 homeownership option to advance home buying by people with disabilities across the country. The programs are taking shape in Colorado and Wisconsin because of progressive housing authorities and the people with disabilities and advocacy organizations that partner with them.

For homeownership to become a realistic housing choice in your state, start with the following steps:

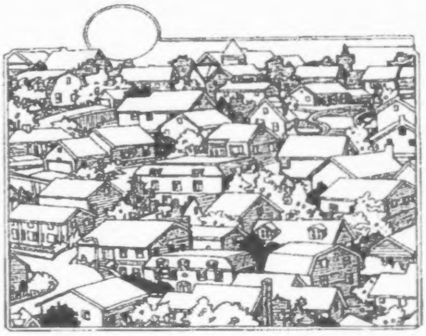
1) **Do the research**. Learn about the new Section 8 homeownership option and what is required of a public housing agency and a homebuyer to participate. Contact lenders and local housing counseling agencies to locate the other mainstream resources you have in your community to support low-income and first-time homebuyers.

To find out more about the HUD Homeownership Program and specialty mortgage products for people with disabilities, go to the national Home of Your Own Section 8 website at <http://alliance.unh.edu/section8finalrule.html> This is by far your best "one stop" information site. You will find the HUD homeownership full rule text and their PowerPoint version, as well as a reader-friendly synopsis of the new voucher option. Also available at the site are an analysis of the HUD homeownership rule and its impact on people with disabilities, and the Colorado Housing Authority program handbook and related materials for establishing the Supported Housing and Homeless Program (SHHP) plan.

To learn about Fannie Mae's HomeChoice mortgage product, a product designed for people with disabilities, go to Fannie Mae's website for "Loans for People with Disabilities" at <http://www.fanniemae.com/neighborhoods/products/housing/loansdisabilities.html>

2) **Contact your local HUD office to get more information and assistance.** Become an advocate expert if you need to do so. Don't be deterred because you don't know enough. Be willing to learn whatever it is that you and others need to know to make the program work in your community. Learn as you go - this is a "new program" and the questions and concerns often shape the answers.

3) **Call your state and/or local PHA** (public housing authority) and ask for their partnership "now" in securing more housing choice vouchers targeted to persons with disabilities in your locale. Remember, the vouchers are the key financial piece to the puzzle. A Section 8 homeownership program with a long wait list for the vouchers won't be as successful as one without a wait list. **Make sure an application for the mainstream vouchers is submitted to HUD by July 20th.** The application site is: <http://www.hud.gov/adm/grants/nofa/grpsec8.html>



4) **Offer your partnership to your state and/or local PHA in establishing the program**. If necessary, convince them to adopt the Section 8 homeownership option for people with disabilities as a means to increase access to a range of affordable, accessible housing in your community.

5) **Assist your state and/or local PHA in designing and implementing the homeownership program** for people with disabilities and be ready to assist with outreach and education. Make sure that the specialized underwriting flexibilities of mortgage products such as HomeChoice are adopted for people with disabilities.

A final thought. Remember that $4.5 trillion dollar "equity and savings in U.S. owned homes" figure from Congress? Well, there are 12 zero places in a trillion dollars - the fully expressed figure is $4,500,000,000,000. Owning a home is about choosing where you live and having the opportunity to live on "a tree-lined main street of America." But the real strength of homeownership as a housing option is that it is not limited to that. Home ownership is also about more people with disabilities investing in their housing and capturing their fair share of those zeros so that they can also live in the "equity-lined main stream of America."

For many reasons homeownership is a good idea. The time for homeownership to become a serious housing choice for people with disabilities has come.

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Expanding our Thinking on Housing Choice

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About the authors: Charlene Dwyer is Executive Director of EbTIDE, Inc. in Wisconsin and a member of the National Council on Independent Living Housing Subcommittee. Jerry Vogt is the Statewide Director of EBTIDE's Homeownership Program. As a person with a significant physical disability and a man before his time, Jerry was a founding member of his condominium association 16 years ago, and made his accessible home affordable with sweat equity. "Because of my quadriplegia, I couldn't hammer nails or paint the walls, but I could make left to right brush strokes and I stained lots of baseboards, ordered construction supplies and kept the accounting records." Today he owns his home in Madison, Wisconsin outright.

For more information on EBTIDE's homeownership partnership programs, visit <http://www.independencefirst.org/Programs/homeownership.htm> or contact Charlene Dwyer at <Chardwyer@aol.com>

Real People, Real Success! Stories from the Colorado Supportive Housing and Homeless Program (SHHP) homeownership program

BY SAM DESIATO

Tim and Lisa

With the help of involved family members and the support of a number of dedicated people, Tim and Lisa were the first people with disabilities to buy a home under the new program. Both are employed and worked extremely hard to reach the goal of a dream home. They pooled their resources with Section 8 assistance to secure a creative financing package that allowed them to obtain their goal - a two bedroom, one bath single family detached home in Montrose (Colorado) that they bought for $82,500 last July.

Tim and Lisa divide the household chores and keep things well organized so that all the usual tasks of a homeowner are accomplished. Tim summed up his feelings about homeownership in a recent Denver Post article, when he said, "We love it. We're staying put." Lisa expressed her sentiments when she said in the same article, "We're staying here for the rest of our lives."

Marcene

Sometimes buying a home doesn't go as smoothly as you would like it to. Marcene ran into a number of hurdles before she could move into her $97,800 duplex in Denver. Some of these challenges were financial in nature, and some were related to her need for modifications to the home so it would be fully accessible. Perseverance on the part of Marcene and all those who assisted her through the process helped get her past the threshold and into her home. And perseverance pays, according to Marcene.

"I think that this is wonderful," she said with a big smile. "Because I'm in a wheelchair, I didn't think anything like this would be possible for me. Owning a house makes me feel like a real person."

From the Executive Director

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to be able to choose to do the things one wants, when he/she wants to do them. This is what makes for good places, and good supports can only be provided in places that support the kinds of freedoms that we all want and expect for ourselves.

Is an organization like TASH still needed? The answer is incontrovertibly yes. As Doug Guess, one of the founders and original board members of TASH recently said, "*TASH has played a major role in helping persuade various states to close institutions, develop community-based services to replace them, and provide educational opportunities in public schools for students with significant disabilities.*" TASH must continue its leadership in the areas of positive behavior supports and systems change, and its work with other individuals and organizations in the disability field to ensure that funding is not placed in the hands of places that do not adhere to best practices and positive behavior supports.

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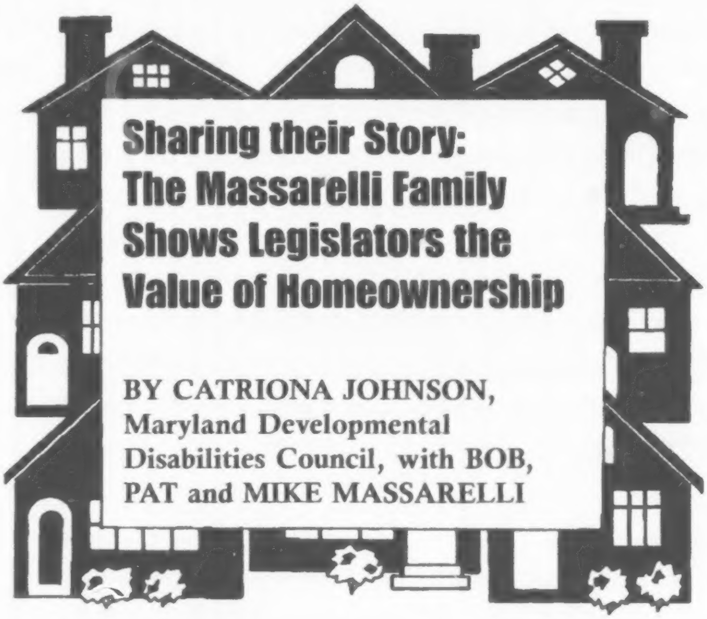

Sharing their Story: The Massarelli Family Shows Legislators the Value of Homeownership

BY CATRIONA JOHNSON, Maryland Developmental Disabilities Council, with BOB, PAT and MIKE MASSARELLI

When the Massarelli family got a call from Frank Hodgetts at Home Partnership, Inc. asking if they were interested in testifying in Annapolis, Maryland about homeownership for people with disabilities, they immediately said "yes." In October of last year Michael Massarelli, now 35, had purchased his first home in Bel Air, Maryland and was living out the American dream of homeownership. He had lived with his family his entire life and both he and his parents, Bob and Pat, knew it was time for him to live independently. When they began thinking about Michael moving out, the idea of homeownership didn't occur to them.

States Pat, "Originally we started looking for an agency that ran its own facility. Gallagher Services began helping us and asked what we thought about Michael living alone. At first this was a bit scary to us, but after much thought we realized that it was a lot easier to live on your own than with someone you don't like."

The youngest of seven children, Michael has cerebral palsy and has worked full-time at Aberdeen Proving Ground-Edgewood Area as a Clerk Typist for the last 12 years. His parents are in their early 70s and wanted to support Michael's move to independence while they were in good health. When Gallagher Services suggested independent housing, Michael began the process of looking for an apartment he could rent. Unfortunately, he couldn't find anything in the area that met his requirements of being near his work and within his price range. That was when the idea of buying a home came up.

Gallagher Services teamed up with Home Partnership, Inc., a housing counseling organization in Harford County, Maryland to assist Michael. Michael completed a homeowner counseling course, and then Home Partnership worked directly with Michael to find out how much he could afford in monthly mortgage payments. Michael was eligible for the State of Maryland's Homeownership for Individuals with Disabilities Program, which provided him with a flexible, low-interest mortgage, and Michael was able to find a house that met all of his needs. Gallagher Services provides drop-in services 4 times a week to assist with activities like going to the bank, shopping, and running errands, and Harford County provides transportation to Michael to get him to and from work each day.

During February and March, Michael, Bob, and Pat all testified before the House Appropriations Committee and the Senate Economic and Environmental Affairs Committee about what the Homeownership for Individuals with Disabilities Program has done for them. Say Bob and Pat, "What it has done for us is given us peace of mind that Michael has his own home and support services. We are very thankful for Gallagher Services. They have been wonderful and we really feel Michael's needs will be met when we are gone. As well, we can now eat when we want to eat or not eat at all if we want to. We have freedom that we didn't have previously and we know that this is the right move for Michael."

For Michael the move has meant increased freedom. He says he was lonely when he first moved away from his parent's home, but now he is beginning to see the advantages. He can socialize with people his own age, and those who have interests similar to his own. A high priority has been his choice of with whom to live. "Since I own my home, I can have a pet. I couldn't have done that in a group home or in a rented apartment," says Michael with a grin.

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Sharing their Story: The Massarelli Family Shows Legislators the Value of Homeownership

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House Bill 1106 (Homeownership Opportunities for Individuals with Disabilities) was introduced by Delegate Mark Shriver (D-Montgomery County), and the bill passed in the Maryland State House. It died in the Senate, but not before Secretary Skinner from the Department of Housing and Community Development agreed to continue funding. Governor Glendening has committed $2.5 million dollars for each of the next three years to continue efforts by the Department of Housing and Community Development (DHCD) to expand homeownership opportunities to low-income Marylanders with disabilities. The Maryland Developmental Disabilities Council led a campaign by the disability community to help the Governor and DHCD understand the importance of supporting additional homeownership activities for people with disabilities. Tireless advocacy from the community and Delegate Mark Shriver was key to winning this commitment from the Governor.

For more information about the Homeownership Opportunities for Individuals with Disabilities legislation in Maryland, contact Catriona Johnson, Director of Public Policy, at the Maryland DD Council, (410) 333-3688 x6 or catrionaj@md-council.org

The Serena Merck Memorial Award

for Innovation and Dedication in Practice 2001

Purpose of the Award The Serena Merck Memorial Award is given annually to an exceptional individual who has demonstrated long-term, selfless dedication and compassion in the care or service to children who have retardation and significant mental health problems. Mrs. Merck recognized the critical importance of what quality day-to-day care provided by committed individuals can make to children with cognitive and behavioral disabilities. The John Merck Fund has established this major, national award to honor her long-standing commitment to this field, and to call attention to the invaluable role caring individuals play in it.

Criteria for Selection of the Awardee Prospective awardees should meet one of the following categories: (1) Provides, as an employee or volunteer, services for children who have mental retardation and significant mental health problems. (2) Demonstrates long-standing commitment and innovative care of this population which has positively affected their quality of life and/or life opportunities.

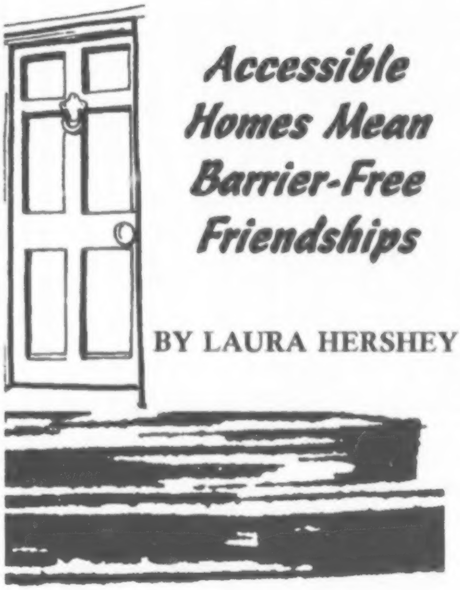
Submission Guidelines Organizational entities may nominate prospective awardees. One nomination per organization is permitted, although multi-service organizations may submit one nomination from more than one service unit. No self-nominations are acceptable. Only organizations serving children with mental retardation and significant mental health problems are eligible to nominate an individual. A 500-word summary of the reason the candidate is nominated, length of service in the field, and a description of the person's impact on children with mental retardation and significant mental health problems is required. At least two, but no more than five, accompanying letters of reference from individuals well qualified to evaluate the candidate's suitability for the award should be provided.

Nominations should be mailed before September 1, 2001, to:
Mr. Frank Hatch, The John Merck Fund,
11 Beacon Street, Suite 1230, Boston, MA 02108

Award A $5,000 cash award and plaque will be presented to the awardee at the 18th Annual National Association for the Dually Diagnosed (NADD) Conference held October 2001, in New Orleans, Louisiana. The awardee's travel expenses to the conference will also be covered.

Accessible Homes Mean Barrier-Free Friendships

BY LAURA HERSHEY



One cold evening in December, I went to my friend Carolyn's 50th birthday party. My partner Robin and I arrived around 9 p.m. We parked our van, went up to the door, and entered, greeting our friends with hugs. We gave Carolyn her presents, and enjoyed her reactions as she opened them. After that, we sat around talking with other party guests, listening to music, drinking red wine. Around 11 p.m., we reluctantly said our goodbyes, exchanged more hugs, and left.

So what? you might be asking. What's the big deal? You're right; it shouldn't be a big deal. It was just a couple of people going to visit their good friends, sharing in an important celebration. It was just a party. It happens all the time, especially around the holidays.

But in one sense, it was a big deal. For people who use wheelchairs for mobility, like Robin and I do, visiting our nondisabled friends is often impossible. Most private homes are completely inaccessible to wheelchair users. American homes are traditionally designed with entrances that require climbing anywhere from two to twenty stairs. Often that means friends, relatives, neighbors, and co-workers are excluded from participation in important social activities, and from the lives of nondisabled homeowners who may never think about the barriers which surround them.

My friend Carolyn and her husband Les, who live in a turn-of-the-century bungalow-style home in northeast Denver, did think about it. And they decided to do something about it. Les and another friend got together one weekend, and they designed and built a sturdy wooden ramp up to the front door. No longer will five steps stand between the Reeds and their friends who use wheelchairs.

I heard from another friend just before Christmas; a wheelchair user who lives in another state, she had the opposite experience during the holiday season. A lawyers' association held its annual holiday reception in a private home with a steep flight of stairs. Despite her longstanding membership, she was effectively barred from attending this important event. The homeowner issued an apology that was as sincere as it was poignant; she admitted that even her own mother, who is mobility-impaired, couldn't visit her inaccessible home.

The apology didn't help my friend get in the door. The same thing has happened to me: I can't count the number of party invitations I've had to decline due to lack of access. And that doesn't even include the parties I wasn't told about, by friends who knew I wouldn't be able to come anyway. This kind of exclusion really hurts. It's one thing when you can't get into a store or a restaurant. You might have the option of suing to demand access improvements. Even if you don't, you can take the sour-grapes approach, spurning one business in favor of another, more accessible one. It's different when you can't get into someone's home, especially when that someone is a friend. Then it's personal. Maybe things are starting to change. As people with disabilities enter professions, community activities, and social circles, more nondisabled people become aware of the kinds of barriers that separate us from them. I have two other friends here in Colorado who, though they themselves do not use wheelchairs, have built ramps so that they can welcome into their homes people who do. Kathy, a member of my writers' group, hired contractors to construct a ramp to the front door of her west Denver home. She's invited me and Robin over for dinner several times. Whenever I visit, I love perusing her collection of feminist books, and colorful craft items from Central America.

And Laurie, a long-time friend of mine who lives in Loveland, offered her brother storage space in exchange for a Saturday spent building a long ramp up to her back door. Last summer she hosted a backyard barbecue. When the rain started to pour, we quickly sought refuge in her small but comfortable house. If the ramp hadn't been there, Robin and I would have had to pack up and head home, missing the rest of the party.

I feel extremely lucky to have friends like these, who can and do invite me into their homes. The fact that they spent time and/or money making their homes accessible feels like both a tremendous complement and a tangible benefit to the community in which we live. These ramps represent solid statements of friendship, and concrete commitments to a belief in nondiscriminatory inclusiveness.

Just imagine a world in which homes were designed to be accessible to everyone! Not just people who use wheelchairs, but everyone. This would not only allow for friends to visit friends. It would mean that when a company or an organization holds a social function in an individual's home, people who use

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2001 TASH Annual Conference: Full Day Institutes

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I-7 Positive Behavior Support: Making It Work For Direct Support Professionals & Families

Facilitated by Scott Shepard

There has been a tremendous need in California to simplify curriculum related to PBS for the families and direct service staff who spend the most time directly supporting children and adults with behavioral challenges. Strategies will be shared for presenting and practicing information related to PBS with families and direct service staff to promote better understanding and success.

I-8 Core Curriculum for All: Strategies for Differentiated Instruction in Inclusive Classrooms

Facilitated by: Mary Falvey, Linda Lee, and Heidi Bjorgan

The morning portion of this workshop will provide information and technical assistance in providing differentiated instruction for students in inclusive settings. Through differentiated instruction, ALL learners will have access to the Core Curriculum. Strategies for adaptations and modifications will be explored to assist students' participation in the core curriculum. In the afternoon, a gout of peer tutors from a middle school will present their program and how they support students in inclusive settings.

I-9 (a) Strategies for Parents to Build Communication Skills to Negotiate Their Children's' Education (conducted in Spanish from 10 a.m. to 12:50 p.m.) (See description below.)

I-9 (b) Strategies for Parents to Build Communication Skills to Negotiate Their Children's' Education (conducted in English from 1:00 - 4:00 p.m.)

Facilitated by Barbara Marbach and Ron Lopez

This workshop will share information and strategies for parents to build communication skills so they can better negotiate for their child's special education services. Communication styles will be reviewed and scenarios from the IEP meeting will be role played so families can learn to become an effective collaborators with their school.

Accessible Homes Mean Barrier-Free Friendships

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wheelchairs would not be excluded. It would mean that when relatives start to age, slow down, and require walkers or wheelchairs, they could still be part of their families' lives.

There's an international movement to try to create just such a world. Concrete Change, based in Atlanta, Georgia, is advocating for a concept called "visitability." Specifically, Concrete Change wants all new housing construction to incorporate basic access features: at least one level or ramped "zero-step" entrance; and doorways (including bathroom doors) at least 32 inches wide. This grassroots group is fighting an uphill battle. The homebuilding industry resists any accessibility mandates, arguing that such requirements will increase home prices. But in fact, building with basic access in mind costs much, much less than retrofitting existing structures.

Despite the obstinacy of the construction industry, Concrete Change can boast of several significant successes. The city of Atlanta passed an ordinance in 1992 to mandate a zero-step entrance in certain private, single-family homes. By 1998, over 500 visitable homes had been constructed under the Atlanta ordinance. The city of Austin, Texas, passed a similar ordinance in 1998. That same year, the British Parliament enacted a law requiring basic access features in new homes constructed throughout England and Wales.

To learn more about Concrete Change, the international effort to make all homes visitable, visit their website at http://concretechange.home.mindspring.com

Laura Hershey is a disability rights leader, poet, writer and trainer. For more information on Ms. Hershey's work, please visit her new web site address, http://www.cripcommentary.com

A Housing Advocate's Resource List

Our thanks to Charlene Dwyer of EBTIDE for compiling and sharing the following list of housing-related resources.

Disability Rights Action Coalition for Housing (DRACH) If you are ready to take action, join today! Contact Karen Tamley, Regional Representative, 301 S. Peoria, Suite 201, Chicago, IL 60607; Phone: 312-226-5900; E-mail: karentam @accessliving.org

Opening Doors <www.c-c-d.org/doors/ html> One of the best housing publications for the disability community by the national Coalition for Citizens with Disabilities (housing issues, trends and concerns). Sign up for your free e-mail or "snail" mail copy today.

Fair Housing Rights and Complaints For a summary of disabled residents' rights under the Fair Housing Amendment, and a description of the seven architectural access requirements, go to <http://www.alpha-one.org/housing.htm> and click on their link to "Accessible Housing Information."

Learn about your fair housing rights and how to file a complaint, file a fair housing complaint on line, print out the complaint form, or get a toll free complaint line number all at <http://www. hud.gov/ hdiscrim.html>

U. S. Department of Housing and Urban Development <www.hud.gov> Links to specific HUD programs and information on disability and other resources <www.hud.gov/fhe/fheacss.html>

Also, information on Section 811 Supportive Housing for Persons with Disabilties <www.hud.gov/progdesc/811main.cfm>

National Home of Your Own Alliance <http://alliance.unh.edu/> A wealth of information on housing for people with disabilities and the best site for "homeownership" information. A one-stop resource site for those interested in HUD's new Section 8 homeownership program with 2 levels of rule overview material, links to HUD's final rule, and sample public housing authority implementation manuals and materials from the Colorado PHA Section 8 homeownership project <http:// alliance.unh.edu/section8finalrule. html>

National Low Income Housing Coalition <www.nlihc.org/> Wonderful source for low-income housing trends and statistics and a great links section

National Council of State Housing Agencies <http://www.ncsha.org/ NCSHA/NCSHAL2/directry/ statindx.html> Find and link to the web page for the housing finance agency for your state.

FannieMae "HomeChoice" Homeownership for People with Disabilities <http://www.fannie mae.com/neighborhoods/products/ housing/loansdisabilities.html> or call 1-800-7FANNIE (Consumer Resource Center) and ask for the account team in the FannieMae regional office closest to you.

The Federal Home Loan Banks The single largest supplier of home mortgage credit in the United States is the Federal Home Loan Bank System (FHLBanks) and their over 6,500 members. The FHLBank System consists of twelve regional FHLBanks. Each bank administers several million dollars in downpayment assistance through the "Affordable Housing Program" (AHP) in partnership with their member banks. Nonprofits may partner with a member bank to apply for, and assist in distributing the downpayment assistance funds. To find the Federal Home Loan Bank in your region, go to <www.fhlbs.com>

Helpful Websites for Visitability, Universal Design and Home Access :

Concrete Change <http:// concretechange.home.mindspring.com> Make new homes in your community "visitable." This site has all the information and guidance you will need to implement "visitability" in your community.

Center for Universal Design <www.design.ncsu.edu/cud> The Center for Universal Design has a long history of conducting research and providing information and services about various areas of housing, including fair housing practices, home modifications and accessible and universal design features in homes. On this sight, you can look at various examples of universally designed, newly constructed homes. Great publications, links and resources!

Adaptive Environments <www. adaptenv.org> A federally funded site which has developed publications to educate about access and universal design.

Center for Inclusive Design and Environmental Access <www.ap. bufalo.edu/%7Eidea> This site provides resources and technical expertise in architecture and product design. Good links section.

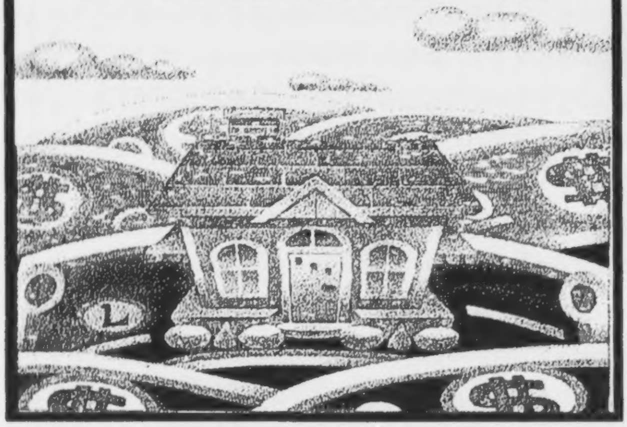
Accessible Design - Accessible Systems, Inc. <www.ad-as.com/> Offers product designs for universal design. Accessible kitchen products, workplace and healthcare furniture. Pricing and catalog available.

Code Requirements for Housing Accessibility <http: //www.bocai.org/ order_building_res.htm>; <http:// www.icbo.org/wsnsa.dll/ prodshow.w?prodid=006S2K>; or <http:// www.sbcci.org/Orders/orders.htm> Visit either of these sites to order a copy of the HUD-endorsed new building code document that clarifies the federal Fair Housing Accessibility Guidelines for builders. These guidelines are designed to help ensure that new apartments and condominiums are accessible to people with disabilities.

The ICC "Code Requirements for Housing Accessibility" (CRHA) is published by the International Code Council (ICC) and was developed through a cooperative effort headed by the National Association of Home Builders and ICC, which also included HUD, building industry representatives and disability rights groups.

Advancing Affordable, Accessible, and Integrated Housing for All Americans

BY JAY KLEIN AND BOB KAFKA



While the number of people living in institutions and large facilities has decreased, the vast majority of individuals residing "in the community" live in residences owned and controlled by someone else. Housing and personal assistance services are dictated far more often by government and agency preferences than by the needs and desires of people with disabilities. Current approaches do not assure that people with disabilities are afforded control over, or even a voice in, the most basic decisions regarding where they live, with whom they live, the nature of the assistance they receive, and how they spend their time. The development of community housing and services for people with disabilities has been a major national policy direction for the past 20 years. Unfortunately, the administrative structures supporting community services typically promote congregate and agency-controlled approaches to housing and personal assistance services.

One Response: Access Housing 2000

Recognizing the need for dramatic changes in policy and practice, the U.S. Department of Housing and Urban Development (HUD), on December 19, 2000, published a notice in the Federal Register on Access Housing 2000. The summary states,

"This Notice provides information on Access Housing 2000, a proposed national initiative that will assist persons with disabilities to transition from nursing homes into the community by providing improved access to affordable housing and necessary personal assistance and supportive services. HUD is partnering with the U.S. Department of Health and Human Services (HHS) and the Institute on Disability (IOD) at the University of New Hampshire to carry out this initiative. Using Section 8 housing vouchers in conjunction with supportive services available under the Medicaid program, the proposed initiative presents an opportunity to design and implement innovative housing and supportive service strategies. If successful, these strategies could expand the availability of accessible, affordable housing in the United States, including homeownership opportunities for persons with disabilities, and assure that such individuals receive the assistance and the ongoing supportive services necessary to make a smooth and successful transition to living in the community."

The Federal Register Notice calls for the Institute on Disability at the University of New Hampshire to create a center to:

"(1) Build broad-based partnerships and collaborations in both the public, private, and advocacy sectors;

(2) conduct outreach to create local coalitions consisting of public, private, and advocacy organizations to build ground-level support for the initiative and to assist in its implementation;

(3) evaluate the efficacy of the strategies developed during the initiative and the dissemination of best practices;

(4) conduct research that examines the process for, benefits of, and barriers to the implementation and accomplishment of the objectives of Access Housing 2000;

(5) examine whether the strategies developed during the initiative can be replicated on a large-scale basis;

(6) analyze Federal and State policy affecting the implementation of this initiative; and

(7) develop a means of ensuring that the experience of the initiative receives broad attention and review, e.g. creating a website."

The December 19, 2000 Federal Register Notice also states:

- *"Access Housing 2000 is a unique partnership focusing on providing a national coordinated response to the Supreme Court's decision in Olmstead v. L.C. (527 U.S. 581 (1999)." Although this is only a small part of their total Olmstead response, HUD and HHS must be commended for putting forth an initiative that recognizes the need to provide ongoing personal assistance services (through Nursing Home Transition grants) that are coordinated but not linked with*

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CHANCE (Center for Housing and New Community Economics) will work to dramatically increase community capacity -- skills, tools and person power -- to assist people with disabilities to transition from all types of institutions and other congregate living environments into the community.

Facilitating broad-based systems change at local, state, and national levels, and fostering partnerships between public and private agencies and foundations concerned with housing, community living, and economic equity will be a major focus of this new initiative.

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integrated, accessible, and affordable housing (through the allocation of housing vouchers).

- *that HUD informed the public in the August 10, 2000 Federal Register of its intention to use a portion of the remaining unobligated Fiscal Year 2000 funds from two Section 8 voucher programs, set aside for people with disabilities, for Access Housing 2000. HUD did not distribute these 400 vouchers in fiscal year 2000. Soon after the August Notice was published, the IOD, ADAPT, and other groups worked with HUD, HHS, and Congress to utilize fiscal year 2001 fair share vouchers instead of using the vouchers that were set aside for people with disabilities. Unfortunately, these efforts were unsuccessful. However, if will use the 400 undistributed vouchers.*

- *HUD will make available, through its funding award process, approximately $2.5 million initially to fund 400 Section 8 vouchers targeted for use by persons with disabilities and families of children with disabilities who currently reside in nursing homes." Therefore, Access Housing 2000 targets people who reside in nursing homes, who are both old and young and may have physical, cognitive or psychiatric disabilities. The initiative has been designed to reach all categorical groups and ages of people with disabilities."*

1990 US Census Bureau figures indicate that 181,270 people younger than 64 years of age live in nursing homes. Braddock, Hemp, Parish, and Rizzolo (2000) reported that 35,887 persons with developmental disabilities currently reside in nursing homes. In addition, the Department of Health and Human Services' Office of the Inspector General attempted to identify the number of people between the ages of 22 and 64 with severe mental illness who live in nursing facilities in its report "Younger Nursing Facility Residents with Mental Illness: An Unidentified Population." In the January 2001 report, the Inspector General states that, "Twenty State mental health authorities (SMHAs) reported a total of 40,277 younger nursing facility residents with mental illness. These 20 States report that, on average, 10 percent of a State's nursing facility population is comprised of younger individuals with a primary diagnosis of mental illness, and 20 percent is comprised of younger individuals with a primary or secondary diagnosis of mental illness."

The Census Bureau reports that in 1990, 4,231 people under the age of 25 lived in nursing homes. This initiative, if allowed to move forward, will afford low-income families the opportunity to use housing vouchers to help establish homes for their children who live in nursing facilities. The housing vouchers, when combined with assistance and ongoing supportive services (which are part of this initiative), will help these children make a smooth and successful transition to living in the community.

In addition, the December 19, 2000 Federal Register Notice:

- *calls for creation of local coalitions consisting of public, private, and advocacy organizations to build ground-level support for the initiative and to assist in its implementation. This required public-private partnership is the initiative's centerpiece. It has the potential of benefiting people with disabilities who live in a variety of institutional settings by affecting systems change at local, state, and federal levels.*

The Notice further states that:

- *Access Housing 2000 will increase the supply of housing for people with disabilities by providing the opportunity, over five years, for 2000 people with disabilities to leave nursing homes and rent or own their housing.*

People with Disabilities Will Have Access to a New CHANCE

On March 18, 2001, the Institute on Disability at the University of New Hampshire (IOD) joined in partnership with ADAPT to announce the creation of the Center for Housing and New Community Economics (CHANCE). The IOD has a proven record of success with its National Home of Your Alliance, and ADAPT has extensive experience in providing technical assistance regarding issues affecting people with disabilities on a national basis. CHANCE will implement the core principles of Access Housing 2000, and will embrace and promote a broader scope of ideals. CHANCE's purpose is to offer alternatives to approaches that segregate, congregate, and control people with disabilities.

Seventeen Public Housing Authorities (PHAs) in eleven states enthusiastically asked to be involved in the Access Housing 2000 initiative. These PHAs overwhelmingly stated that they wish to use the vouchers to assist people to obtain integrated, affordable, and accessible housing. The Access 2000 initiative is not only designed to create housing options, but will also ensure that people with disabilities are afforded the opportunity to direct all aspects of their lives. Access Housing 2000 will assist Public Housing Authorities and Medicaid agencies to develop the capacity and collaborations necessary to assure people with disabilities rent or own housing that is coordinated with personal assistance and supportive services. People with disabilities can use the vouchers to rent apartments in privately-owned buildings, assisted living facilities, or residential facilities, or to eventually own accessible and affordable homes.

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CHANCE: A Broader Approach

The approach of CHANCE will be based on a clearly defined set of principles promoted by the Institute on Disabilities, ADAPT, and their collaborators for several years. These principles pertain to both attitudes and practices and will guide all aspects of center activities. These guiding principles are:

❖affordable, accessible, integrated housing must be attainable for all Americans

❖while people with disabilities may need personal assistance services and integrated, accessible, and affordable housing, it cannot be mandatory that housing assistance be linked to one's participation in or need for other types of services; any resistance and barriers which may impede ability to access individualized personal assistance and support services to live in the community must be overcome;

❖people with disabilities must be afforded the opportunity to direct all aspects of their lives, including selecting and controlling their homes and apartments, services and supports, funding, planning, and coordination activities;

❖an initiative that succeeds in bringing about accessible, and affordable housing and personal assistance for people with disabilities will require systems change at the local, state, and federal levels and the collaboration of the public and private sectors; and

❖the degree to which the guiding principles can be replicated is enhanced through sensitivity to state and local issues, and practical support by highly competent experts (including people with disabilities and their families).

The IOD and ADAPT intend to collaborate with a broad array of "like minded" individuals and organizations concerned with housing, personal assistance, and economic equity. CHANCE will bring together numerous private and public national financial institutions, advocacy organizations, federal and state agencies, foundations, civic and community associations, and others. These collaborators will accomplish the work of CHANCE in partnership with people with disabilities, and families.

The role of collaborators will be to provide information and technical support related to integrated, affordable, and accessible housing coordinated with, but not linked to, personal assistance. This support may include working with housing agencies and lenders; creative finance and underwriting; pre- and post-purchase and rental counseling; home selection; and design, renovation, maintenance, and architectural barrier removal for housing that is rented or owned. Other available assistance will include technical support with accessibility, Nursing Home Transition Grants, the use of Section 8 housing vouchers and other rental assistance in conjunction with innovative services offered through the Medicaid program, and implementation of Olmstead-related activities.

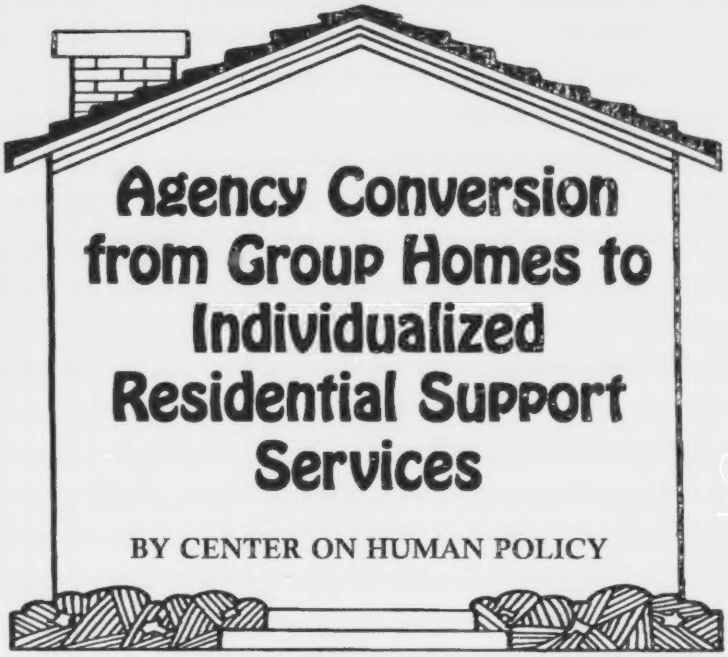
CHANCE will work to dramatically increase community capacity - skills, tools and person power - to assist people with disabilities to transition from nursing homes, institutions and other segregated, congregate living facilities into the community. CHANCE will promote innovative, field-tested, state-of-the-art strategies (based on real life experiences) to increase the number of people throughout the country who make successful transitions.

Access Housing 2000 is explained by HUD in the December 19, 2000 Federal Register and by the Department of Health and Human Services in a letter sent to State Medicaid Directors on January 10, 2001 titled "Olmstead Update No: 5." Both of these documents are available by clicking on Access Housing 2000 at www.alliance.unh.edu

If you are interested in signing on as a collaborator of CHANCE, log on to www.alliance.unh.edu or e-mail Jay Klein at chance.iod@home.com or Mike Auberger at chance.adapt@home.com

Reference:

Braddock, D., Hemp, R., Parish, S. and Rizzolo, M. (2000). State of the States in Developmental Disabilities 2000 Study Summary. Department of Disabilities and Human Development, University of Chicago.



Agency Conversion from Group Homes to Individualized Residential Support Services

BY CENTER ON HUMAN POLICY

Increasingly, agencies that traditionally offered a group home model of service are interested in converting to more individualized residential supports. This article is based on interviews with people associated with agencies (including administrators, people who receive support, direct support staff, Board members, families) that have converted. They include agencies that have converted services for less than 20 people to those that have converted services for over 200. This paper highlights some of the key issues in conversion across these agencies. These include themes related to: impetus for conversion, strategies, challenges, and lessons.

Impetus for Conversion

There were three central reasons for agency change. Often, however, the impetus for change involved aspects of all three of these areas.

❶ ***Discovering dissatisfaction with traditional services***. Some of those who were interviewed described reaching an awareness that people in the group homes operated by the agency were not satisfied. Sometimes this awareness came about through the agency's own inquiries regarding people's satisfaction, and sometimes through external evaluation processes. For example, one agency representative reported that after conducting a consumer satisfaction survey, "We discovered everybody wasn't as happy as we thought they were." Dissatisfaction was expressed in a variety of ways, ranging from general unhappiness with life in a group home, to incidents of behavior that was harmful to the person and/or others.

❷ ***Organizational and fiscal difficulties***. Another impetus for conversion was that some agencies were experiencing organizational and fiscal difficulties. As a result of these difficulties, they made administrative and/or Board changes that would address these issues and at the same time lead the agency in the direction of conversion to individualized support services.

❸ ***Inspiration from others***. Finally, agencies were inspired to change by conferences or other forums where they heard stories of other agencies around the country that were using an individualized support approach. As one director explained, "We became convinced there was a better way for people to live."

Strategies

There were many similarities across agencies in terms of strategies that they used in the process of closing group homes and offering individualized supports.

- **Examination of agency mission and values**. Often, the process of change was connected to a statement, or restatement, of the agency mission and values. This included a radical shift in the position of people with disabilities within the agency—from recipients of services to central decision makers regarding where they would live, with whom they would live, and who would support them, as well as participation in organizational decision making. This focus on mission and values was sometimes accompanied by an organizational or strategic plan. Shifting agency values and direction was a process that took time and hard work. For example, in some agencies, there was a symbolic attachment to the facilities; one agency representative reported, "We had a big discussion about what was the agency—the building, or the service?" Those who were interviewed felt it was desirable, though not necessary, to have unanimous agreement among the Board and agency administration regarding agency change, but that it was critical to have a solid core of people who were committed to this, including some in leadership positions.

- **Examination of agency coherence with mission and values**. Once agency mission and values were clarified, a next step was examination of agency services for coherence with these. Agency change did not just mean offering individualized supports to some people; it meant a commitment to a process of conversion of all agency services. Often, this was accompanied by a commitment to use of self-evaluation as well as outside consultants and evaluators to help plan and assess changes, as well. In some cases, agencies obtained grants to help pay for outside consultants.

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- **Creating individualized opportunities for people with the most severe disabilities**. In beginning to create individualized alternatives, a common strategy among the agencies was to intentionally include some people with the most severe disabilities among the first for whom changes were made. Initially, they saw this as an opportunity to learn for themselves what it would take to support all people in the community.

- **Sharing success stories and other lessons**. Once some individualized supports were in place, these examples could be used in a number of ways. They could be used to give positive energy and feedback to agency staff to continue the hard work of change. In addition, they could be used to educate skeptical families and other community members. It was particularly critical that some of these examples included those with the most severe disabilities, so that everyone could see that individualized supports could apply to all people.

- **Reaching out to families and the community**. Implementation of individualized supports was accompanied by increased collaboration with families and other community members. For families who were anxious about the change, agencies spent time in meeting with them and shared "success stories" with them. One agency representative noted, "Often, parents who were against this change, after seeing some successes, changed their minds." Agencies also have reached out families and to the community in a number of other ways: they have encouraged family members (who were not already involved) and other community members to become part of support circles; they have assisted people they support to develop and/or strengthen individual connections with family and other community members; and they have found support for the agency as a whole from families and other community members and community organizations.

Agencies found that the service system was sometimes responsive to the development of individualized supports, but that this occurred more often on an individual basis, where consumers, providers, advocates, and families were bringing forward demands, rather than on a routine, system-wide basis. As a whole, there were still many systems barriers and disincentives to the development of individualized supports.

- **Supporting staff**. Many, though not all, agency staff prefer their work doing individualized supports as opposed to facility-based supports, and most agencies reported less staff turnover after conversion. There were a number of steps that agencies took to help support staff in this transition.

One aspect of conversion involved retraining staff in areas such as: what supported living is, and how it is different from facility-based supports; person-centered planning; and developing natural supports. In some cases, agencies obtained grants for some of this staff training, and were able to involve outside consultants. Another aspect of conversion involved efforts to give increased recognition and support to direct service staff, in order to help create and sustain positive energy. This included, where possible, increasing staff salaries, and/or giving bonuses. It also included helping staff to feel a part of a team (e.g., with families, agency administrators, and others). And, it included giving recognition to staff for successes as well as support to staff for problem-solving.

- **Use of creative financing**. Supporting people with severe disabilities in individualized ways has entailed use of creative financing strategies. This has included creatively combining rates and/or funding sources, requesting rate increases, negotiating for "bridge funding" to help with transition, and writing grants that support organizational change and development. It has involved working closely with and developing positive relationships with local, regional, and state administrators of disability services, as well as working in collaboration with banks, housing organizations, and other community groups. One agency representative reflected on their work with the local housing authority: "At first they weren't used to dealing people, rather than agencies; they weren't used to giving money to people directly, especially people with disabilities."

Challenges

Agencies discovered numerous challenges to conversion. Some of the key challenges are summarized below.

Financial difficulties. There were two areas of issues related to finances: funding for support services and funding for direct staff salaries. Most agency representatives reported that funding levels were not adequate to support people with severe disabilities, so they have to use creative means in order to figure this out. Also, some agencies reported that the funding structure is inflexible, and does not allow for changes in people's needs. Categorical funding can pose restrictions on agencies. As one agency director put it, "We want to serve people, not categories." Also, funding levels are not sufficient to adequately reimburse staff; agencies try to do what they can to give bonuses and other incentives to staff, but they are disturbed by this and fear burning out staff who are underpaid.

Transportation. Those who were interviewed reported that transportation

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is still a major factor that limits where people can live, where they can work, and when and with whom they can socialize.

Maintaining paid and unpaid support, as well as other community connections. As one agency director described, "This is endless work." For agencies that rely on housemates, there is the ongoing work of recruiting and supporting them. There is also the ongoing work of developing and strengthening circles of support and social relationships, particularly for those who do not have family, but also for those whose support circles and friendships consist primarily of family and paid staff. In addition, within support circles, there is sometimes ongoing work involved in balancing power and control issues.

Running a dual system. Some agencies reflected that the most difficult part was "running a dual system" of services part way through the conversion process. This entailed trying to balance resources and energy toward maintaining the group homes for people who were still there, and at the same time working to develop integrated community supports.

Lessons

Finally, throughout the course of agency conversion, there were a number of lessons learned. A few of these that stood out for those who were interviewed are summarized here.

❖ **People who are supported seem to be doing better**. A board member described that, before their conversion, "people were in captivity." Across agencies, people with disabilities and family members who were interviewed indicated much greater satisfaction with individualized services. Administrators also felt that people who they supported were more content. For instance, a director of one agency observed that people seem "more relaxed, more at ease, less threatened." Also common across agencies was the observation that most issues of challenging behaviors diminished if not entirely disappeared with a conversion to individualized services.

❖ **Conversion is not an endpoint.** Agencies realized, during the course of conversion, that this would not be an endpoint in assisting people to have better lives, but that it would be a new starting point. Agency representatives agreed that while people's living situations are better, they are not necessarily optimal. So, there will be need to keep listening to and learning from the people they support. In addition, for some agencies, closure of group homes raised other glaring issues that need to be addressed in people's lives—for instance, the still highly segregated and facility-based day services, particularly for those with severe disabilities.

❖ **Systems can be responsive, but...?** Agencies found that the service system was sometimes responsive to the development of individualized supports, but that this occurred more often on an individual basis, where consumers, providers, advocates, and families were bringing forward demands, rather than on a routine, system-wise basis. As a whole, there were still many systems barriers and disincentives to the development of individualized supports.

In conclusion, those who were interviewed acknowledged that "going from theory to practice is a huge amount of work." During the course of this work, there was need to balance the desire to proceed slowly and carefully with the urgency to assist people in having better lives. Finally, two of the critical keys to successful conversion are "persistence and collaboration."

Additional Resources

Hulgin, K. (1996). Jay Nolan Community Services: The advantages and dilemmas of converting quickly from group homes to supported living services. Syracuse, NY: Center on Human Policy.

Kendrick, M. (n.d.). Lessons from the replacement of a group home with other personalized options. Holyoke, MA: Kendrick Consulting Services.

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TASH NEWSLETTER

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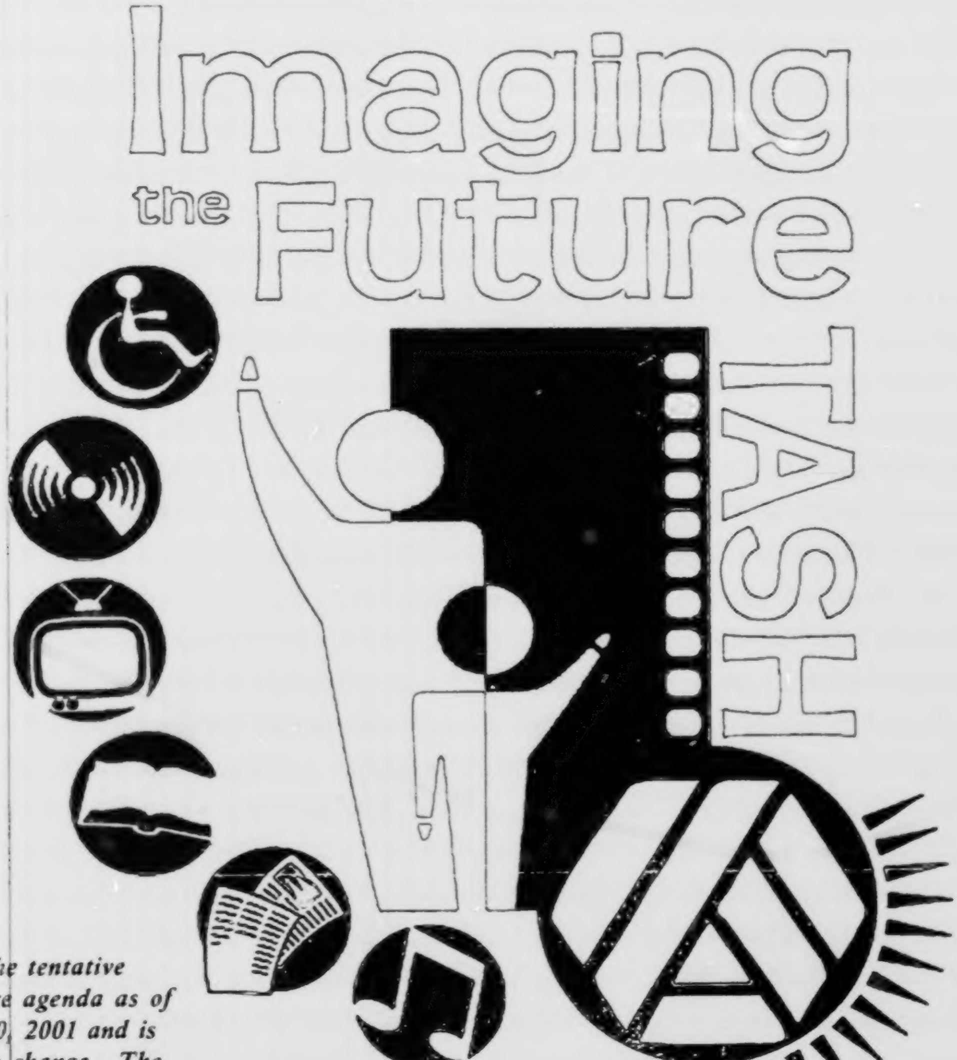
TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

2001 TASH Conference

Co-Sponsored by CAL TASH



This is the tentative conference agenda as of August 10, 2001 and is subject to change. The official conference program is distributed on-site.

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

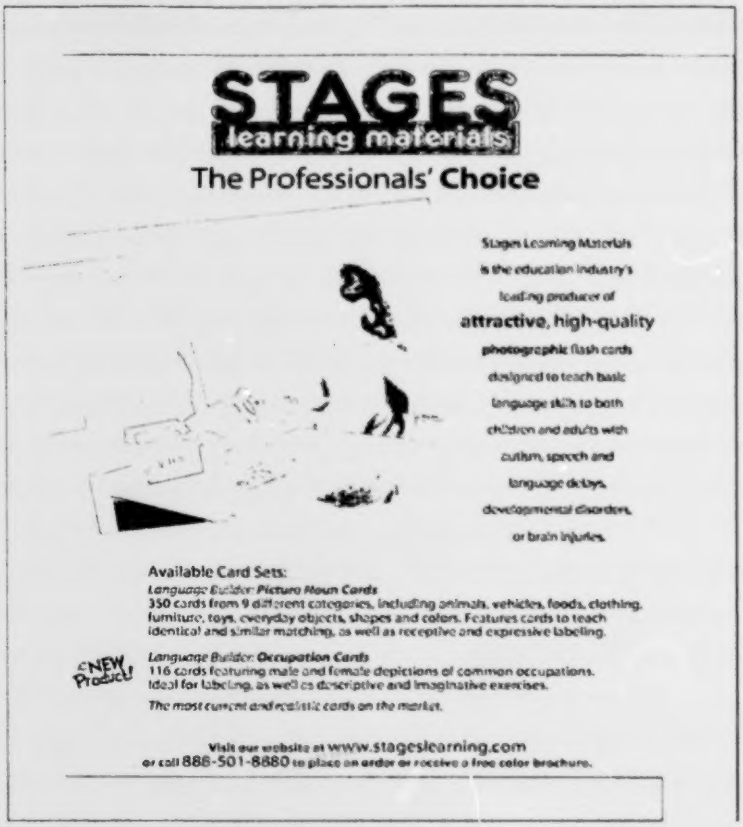
Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

Supporting progressive legislation and litigation; and,

Promoting excellence in services.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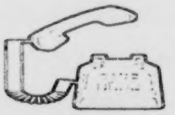
learning materials
The Professionals' Choice

Stages Learning Materials is the education industry's leading producer of attractive, high-quality photographic flash cards designed to teach basic language skills to both children and adults with autism, speech and language delays, developmental disorders, or brain injuries.

Available Card Sets:
Language Builder: ***Picture Noun Cards***
350 cards from 9 different categories, including animals, vehicles, foods, clothing, furniture, toys, everyday objects, shapes and colors. Features cards to teach identical and similar matching, as well as receptive and expressive labeling.

NEW Product!
Language Builder: ***Occupation Cards***
116 cards featuring male and female depictions of common occupations. Ideal for labeling, as well as descriptive and imaginative exercises.
The most current and realistic cards on the market.

Visit our website at www.stageslearning.com
or call 888-501-8880 to place an order or receive a free color brochure.



WHOM DO I CONTACT??

- ☐ **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- ☐ **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- ☐ **For questions about the 2001 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- ☐ **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- ☐ **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
- ☐ **For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- ☐ **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- ☐ **Don't forget to visit TASH's web site at http://www.tash.org**

TASH Connections is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in TASH Connections should be sent to: TASH Connections, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Connections Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

From the Executive Director
BY NANCY WEISS

What do you think of when you think of a TASH conference? For those of you who have attended one (or many!) you know that TASH conferences have little in common with conferences characterized by a litany of dry, take-a-look-at-the-findings-of-this-obscure-research kind of presentations.

Recent conference goers have described the TASH conference as "embracing," "rejuvenating," "action-oriented," "fun," and "vibrant." One advocate said, "Of course, the TASH Conference isn't so much a conference as it is a happening!" TASH isn't a professional association; it isn't a parent organization, nor is it a self-advocacy group. Rather TASH is a true blending of all three of these - an association of people from all walks of life who are concerned with the most important issues facing people with disabilities and their families. Only within TASH do parents, self-advocates, researchers, students, and professionals come together to create an unstoppable movement for social change. The conference is the embodiment of TASH's spirit, a place where you will feel welcomed, included, challenged and energized by the incredible variety of new ideas you'll encounter and new people you'll meet.

This year's conference includes some tried-and-true events as well as some things that are new this year. You will still find the country's best array of conference sessions on the topics that are of the greatest interest to people with disabilities and their advocates:

- **making inclusion work**
- **community living**
- **self-advocacy**
- **family issues**
- **early childhood**
- **communication**
- **employment**
- **criminal justice**
- **governmental affairs**
- **sexuality**
- **alternatives to guardianship**
- **transition**
- **seeking to understand autism**
- **personnel preparation**
- **critical ethical issues**
- **positive behavioral supports**
- **multicultural issues**
- **recreation and leisure**
- **voices of friendship**
- **research**
- **related services**
- **higher education**
- **spirituality**
- **school reform**
- **alternate assessments, and more**

This year we are continuing last year's highly successful **Roundtable Lunch** opportunity. Sign up in advance for a box lunch, then choose a table marked with a discussion topic of your choice. Meet with national experts, researchers, direct support professionals, educators, parents, self-advocates and others, around the topics that are of most interest to progressive disability activists today. Have a discussion topic you'd like to see discussed? There's still time to make a recommendation (e-mail Kelly Nelson at knelson@tash.org).

Also back by popular demand this year is the **exclusive exhibit and poster session time** on Saturday morning with a complimentary continental breakfast provided.

Saturday Institutes are a new addition to this year's meeting, and we hope all conference attendees will take advantage of the opportunity to attend a full-day session at no additional cost (see page 9 for details). Local attendees and others who cannnot attend the full conference will have the opportunity to attend the Saturday Institutes for a nominal fee.

Exclusive to this year's conference is the **Image Awards Forum and Reception**. The theme for this year's conference is "Imaging the Future." How do the images of people with disabilities portrayed in advertising, movies, on TV, and through other forms of media affect the way society views people with disabilities? What can be done to assure that positive images are promoted? The conference will include speakers, a panel discussion, and a reception/showcase highlighting the most important successes in positive media imagery of people with disabilities.

Also featured at this year's event will be opportunities for people looking to "hook up" with new people at the conference. Each evening we will organize a meeting place for folks interested in connecting with others for dinner. Even if you are attending the conference alone, you will have a way to meet others from across the country and around the world for enjoyable dining and great conversation. Everybody is welcome!

Friday afternoon's **rally in support of community living and equitable wages** and benefits for those who provide assistance, support and services to people with disabilities is sure to provide a sense of solidarity for the cause of community.

Finally, for the first time in many years, the conference in Anaheim will end on Saturday afternoon with a moving **closing gathering** that will give us the energizing spirit that each of us needs to move forward the ideas we will take with us.

We welcome you to take a look at the descriptions of the plenary sessions, hundreds of exciting concurrent sessions and the incredible speakers that this year's conference has to offer. We look forward to seeing you in Anaheim!

2001 TASH KEYNOTE SPEAKERS

Daniel Keplinger

Daniel Keplinger, about whom the Academy Award winning film, *King Gimp*, and the stunning and powerful Cingular advertisement released during the Super Bowl were made. Throughout his life, in words and actions, Dan has embodied the values of TASH. We are pleased that he will be joining us in Anaheim, helping to shape an incredibly powerful dialogue about the role of media and advertising in changing the images of people with disabilities.

Tari Susan Hartman

Tari Susan Hartman's EIN SOF Communications is the leading marketing, special events, and public relations company specializing in disability, diversity, and social issues. Some of EIN SOF's clients include Microsoft's Accessible Technology Group, Cingular Wireless, Nickelodeon's launch of their John Callahan animated series, *Pelswick*; and the full spectrum of national disability organizations. Tari has been actively consulting with and creating synergy with the disability community, media, corporate America, government, and the public for many years.

John T. Sanford, Esq.

John Thomas Sanford, III, is a practicing attorney in the State of Michigan and currently serves as the Co-founder and Chairman of The National Family for the Advancement of Minorities with Disabilities. For more than twenty years, John has used his legal expertise and personal commitment to actively battle for the civil rights of persons with disabilities. John will address what he believes is the fallacy that the disability rights movement has been operating under, which is that it is a "melting pot" when it comes to addressing disability issues. He believes this fallacy has falsely led the movement to be under the impression that is has addressed the issues of all people with disabilities, when in fact it has in effect ignored and devalued the issues and concerns that uniquely affect people of color with disabilities. John urges the TASH membership to embrace disability issues from a "salad bowl" approach instead.

Caroline "Ann" Thomas

Caroline "Ann" Thomas is an internationally accomplished self-advocate who travels throughout the US and abroad consulting and speaking about issues relating to self-determination, self-advocacy, and systems change. Ann is the incoming President for People First in Ohio and is a member of many statewide and national committees. Ann is very proud to be on the Robert Wood Johnson's Self-Determination Grant Steering Committee for the State of Ohio.

◇◇◇◇◇

Other invited General Session speakers not yet confirmed as this issue went to press include:

- ○ Robert Pasternack, Assistant Secretary of Education, OSERS
- ○ Julie Clark, U.S. Department of Labor, Presidential Task Force on Employment

Look for information about these and other invited speakers on TASH's website <www.tash.org> and in upcoming issues of TASH *Connections*.

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Joint Strategic Planning Session Planned for Anaheim!!

A strategic planning session will be held in conjunction with the conference on **Saturday, November 17th from 1:00 - 4:00 pm.** The purposes of this session will be to:

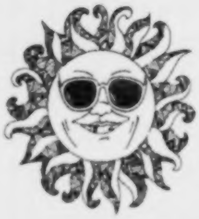
- Identify what the TASH committees, chapters, members, staff and Board have accomplished toward meeting the goals of the current strategic plan.
- Review and discuss the proposed mission statement and new names for TASH. A final recommendation on a new name will be made by the people attending the strategic planning session in Anaheim. It is planned that a decision on a new name will be finalized by the Board at their meeting following the strategic planning session.

All chapter officers, committee chairs, Board members and staff are invited to participate! All chapters and committees are encouraged to have at least one representative attend this important meeting. If you would like to attend (but are not a committee or chapter representative), please contact Nancy Weiss at <nweiss@tash.org> or indicate on the conference registration form (page 11) that you plan to attend. We welcome the participation of all TASH members as space allows.

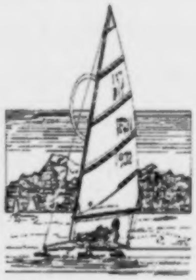
Want to have your voice heard on the new name proposals? At the conference, all members will be given an opportunity to participate in a poll to indicate your choice for a new name from the options proposed by the New Name Committee.

CAL TASH welcomes TASH

To Southern California



Please join us for
Music, Appetizers,
and a No Host Bar
Wednesday, November 14th
6:00 - 8:00 p.m.



Guest Speaker:
Laura San Giacomo
Star of the hit NBC show,
"Just Shoot Me"
"How Inclusion Has Touched My Family"

Networking!

- CAL TASH Award Presentations Ceremony
- Robert Gaylord Ross Award for Scholarship
- Bill Rosenberg Service Award
- Mary Falvey Young Person Award

FUN!

Meet the CAL TASH Board

Purchase raffle tickets

Bid on Silent Auction Items

(Raffle and auction end Friday, November 16 at 7:30 p.m.)

With its shared focus, TASH incorporates everyone who has an interest in the full inclusion of people labeled with the most significant disabilities. People who, traditionally, have been denied access to quality education, valued employment, and the right to inclusive community living.

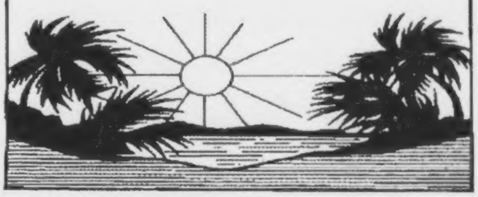
With its focus on best practice, TASH provides a forum for individuals with disabilities, families, researchers, educators, scholars, and others to create dialogue around innovative supports. With its focus on creating change, TASH provides a forum for social and systems reform. And for many, TASH provides a mechanism for renewing the spirit, lifting the heart, and challenging the mind.

This unique gathering has a synergy and motivation surpassed by none. The theme of the 2001 TASH Conference "Imaging the Future" is about recognizing the power of tangible or visible representations projected through the mass media. The images projected by film, art, music, news, movies and other mediums create perceptions and popular societal attitudes about people with disabilities.

Beliefs or perceptions can become so powerful that they obscure reality, and as we know, create barriers to acceptance and belonging. This conference celebrates images and innovations that have contributed to positive and empowering perceptions and beliefs about the inherent value and contribution citizens with disabilities bring to and deserve from society. Join us as we seek to bring solidarity around this issue to ensure media images is value, acknowledge, and welcome civic participation of individuals with disabilities.

"IMAGING THE FUTURE"
2001 TASH Conference

Anaheim, California
November 14-17, 2001



2001 TASH Conference Hotel Information

The conference hotel is the Anaheim Marriott, located at 700 West Convention Way, Anaheim, CA 92802, Phone: 1-714-750-8000, Fax: 1-714-750-9100, or Marriott Worldwide Reservations 1-800-228-9290.

This year for the first time you can make hotel reservations for the TASH conference directly on the web using the following Group Codes:

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Tentative Conference Agenda

Wednesday, November 14th

10:00 am - 2:00 pm	Registration Open
1:00 pm - 6:00 pm	TASH Tech Pre-Conference Workshop
2:00 pm - 8:00 pm	Registration Open
6:00 pm - 8:00 pm	Opening Reception (sponsored by Cal-TASH)

Thursday, November 15th

7:00 am - 10:00 am	Exhibitor Set-Up
7:00 am - 2:00 pm	Registration Open
8:30 am - 10:00 am	Opening General Session
10:00 am - 1:00 pm	Exhibits Open
10:30 am - 5:45 pm	Conference Breakout Sessions
1:00 pm - 2:15 pm	Roundtable Luncheon or lunch on your own
2:30 pm - 6:00 pm	Exhibits Open
5:45 pm - 7:30 pm	Reception honoring award winners

Friday, November 16th

7:00 am - 12:00 pm	Registration Open
8:00 am - 5:00 pm	Conference Breakout Sessions
8:00 am - 10:30 am	Exhibits Open
10:30 am - 12:00 pm	General Session
12:00 pm - 12:45 pm	Break
1:30 pm - 7:30 pm	Exhibits Open
5:00 pm	Rally and Press Conference
5:45 pm - 7:30 pm	Reception in Exhibit Hall

Saturday, November 17th

7:00 am - 10:00 am	Registration Open
7:30 am - 10:00 am	Poster Presentations
8:00 am - 12:00 pm	Exhibits Open
10:00 am - 2:15 pm	Conference Breakout Sessions
10:00 am - 4:00 pm	Full Day Institutes
12:30 pm - 1:30 pm	Closing Gathering

"IMAGING THE FUTURE" 2001 TASH Conference

Continued from page 6

Group Codes for the Web

Single room code - CITCITA
Double room code - CITCITAB
Triple room code - CITCITAC
Quadruple room code - CITCITAD

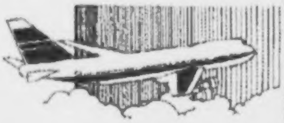
Be sure to mention that you are making reservations for the TASH Conference to take advantage of these reduced rates.

Single Room - $140.00 plus tax
Double Room - $160.00 plus tax
Additional Person $20.00

Please be advised that the above rates do not include current room tax, which is 15%. The block of rooms held for the TASH Conference is being held until October 14, 2001. When the block is full, or after October 14th, rooms will be available if space permits, however, they may be at a higher rate.

For accessibility, roommate referral, personal assistants or other accommodation-related questions, please call 1-800-482-8274 or send an e-mail to <dmarsh@tash.org> This is a smoke and scent (perfume/cologne) free conference.

Official Conference Airlines



Southwest and **United** will be the official conference carriers this year. You can make reservations directly with the airlines, or through a travel agent. Please be sure to reference the applicable ID Code to receive travel discounts. Flying with Southwest or United also enables TASH to offer scholarships for family members and individuals with disabilities to attend future TASH Conferences, as we earn one round-trip ticket for every 40 attendees that fly on the official conference airlines.

Southwest Airlines is offering a 10% discount on most of its already low fares for air travel to and from the TASH Convention. You or your travel agent can call Southwest Airlines Group and Meetings Reservations at 1-800-433-5368 and reference **TASH ID Code: R7304**. Reservation sales agents are available from 8:00 a.m. - 5:00 p.m. Monday -Friday or 9:30 a.m.- 3:30 p.m. Saturday and Sunday in all time zones. You must make reservations five or more days prior to travel to take advantage of this offer.

United Airlines is offering a 5-15% discount on air travel to the TASH Convention. You or your travel agent can call United at 1-800-521-4041 to book a flight. You will receive a 5% discount off the lowest applicable discount fare, including First Class or a 10% discount off of full fare unrestricted coach fares purchased 7 days in advance of travel. An additional 5% discount will apply for tickets purchased at least 60 days in advance of the travel date. Discounts also apply to Shuttle by United and United Express. Please be sure to reference **TASH Meeting ID Number 594XG**. Reservation agents are available 7 days a week from 7:00 a.m. to 12:00 midnight EST.

IMAGES FORUM, Thursday, Nov. 15

From 3:30-5:45 pm, join us for an incredible Forum at which a solidarity statement will be formulated around the use of media to positively portray and empower people with disabilities.

The Forum will be moderated by Marcie Roth and Tari Susan Hartman, chairs of the Media Images Committee. Panel members will include media activists Mary Johnson, Janine Bertram Kemp, Jennifer Burnett, Steve Drake and others. Invited panelists from the advertising, news, television and film arenas will also be represented.

University of Toledo
COLLEGE OF EDUCATION

Tenure Track Faculty Position in Area of Special Education - Severe Disabilities

Advanced Assistant or Associate Level Professor (Severe Disabilities). Faculty member will coordinate undergraduate and graduate degree programs in area of severe disability, with emphasis on persons with developmental or behavioral disabilities.

Candidates should have established an emerging record of higher education teaching, publication, conference presentations, grant support, and professional service focused on persons with severe disabilities. Earned doctorate in special education. Previous professional or classroom teaching experience is desirable. Salary and benefits are competitive and include summer session option.

Application deadline is January 15, 2002. Please send curriculum vitae and 3 letters of reference to: Dr. William Gray, Coordinator of Faculty Search Committee, College of Education, Snyder Memorial, 2810 W. Bancroft, Toledo, OH 43606. Please contact Dr. William McInerney via e-mail (william.mcinerney@utoledo.edu) or phone at (419) 530-2284 with specific questions re: area of severe disability.

The University of Toledo is a state-supported, comprehensive doctoral level institution and is an equal access, equal opportunity, affirmative action employer and educator.

TASH TECH Pre-Conference, Full-Day Workshops

Wednesday, November 14, 2001
1:00 - 6:00 p.m.

TASH TECHs are 5-hour, pre-conference workshops. There is an additional fee for attendance to these workshops, and pre-registration is required to guarantee seating.

T-1 If Everyone Agrees This IS SO Important, Why DO SO Few Kids Have Friends?

Facilitated by Carol Tashie and Zach Rossetti

Most people agree - friendship and relationships truly do make the world go 'round! However, many parents of children with disabilities report that their sons and daughters are lonely and lack meaningful relationships with classmates and friends. This workshop is designed to identify some of the real barriers to friendship and spark discussion on the strategies to support meaningful relationships for all children and youth. Through the use of the video "Voices of Friendship" the participants will learn about the relationship of five teenage girls and the lessons they have taught us on how to facilitate real friendships.

T-2 Using Internet Tools to Enhance Collaboration and Provide Training and Technical Assistance to Service Providers and Families: A Hands-on Demonstration

Facilitated by Richard Kiefer-O'Donnell and Fred Spooner

This workshop will demonstrate and train participants in how to use video conferencing, threaded discussions, chats, application and file sharing, whiteboards, and online broadcasts (webcasts) for team collaboration and provision of technical assistance at a distance.

T-3 Changes in Latitude, Change in Attitude: The Essential Role of Inclusion Facilitator in Promoting Full Inclusion

Facilitated by Cheryl Jorgensen, Zachary Rossetti and Sharon McGovern

For schools to become inclusive, the role and title of special education teacher must change to that of Inclusion Facilitator. This full day workshop will present examples of the beliefs and skills necessary for supporting school communities to embrace inclusion.

T-4 Designing and Implementing Inclusive Curriculum: Teaching, Community and Standards

Facilitated by Mara Sapon-Shevin, Mary Fisher, and Paula Kluth

This interactive workshop will address strategies for designing and implementing inclusive curriculum for heterogeneous learners. Ways of incorporating state standard and IEP objectives within rich, cooperative, multi-level curriculum will be explored and experienced by workshop participants.

T-5 Literature-Based Language Intervention for Students Who Use AAC

Facilitated by Amy Staples and Beth Foley

This session will provide participants with current research findings regarding language and literacy development for AAC users, a framework for implementing literacy instruction, and an array of strategies for promoting interaction during literacy-based activities for elementary through high school students.

T-6 Partners in Justice

Facilitated by Debbie Gilmer, Diane Nelson-Bryen, Helen Bailey, Alan Hammond, Alan Kurtz, and Kathy Son

Every day people with mental retardation come face to face with the criminal justice system - as victims of crime, witnesses to crimes and as people accused of crimes. In this interactive workshop for criminal justice personnel, attorneys, advocates and others, the Maine Partners in Justice team will share strategies for getting relevant training to the front lines. Participants will receive a CD with the Maine version of the curricula.

T-7 Creating Inclusive Childcare Settings

Facilitated by Pam Miller and Peggy Florio

This workshop will provide information on facilitating the collaboration of families, childcare professionals and other education and service agencies to successfully include children of all abilities in community settings. A variety of strategies offered by certified Project ACT teachers designed to educate child care providers, Head Start teachers, and public school teachers, as well as parents, the community, and other professionals will be presented.

T- 8 Creating Successful Experience for All Students Through Positive Behavioral Supports

Facilitated by Deborah Heeden, Barb Ayres, and Susan DeLuke

This interactive workshop will provide participants with information on positive behavioral supports. Key components that will be explored include: understanding your own attitude or posture; acknowledging the function of behaviors; gathering information about the student; and determining how difficult behaviors can be prevented. Participants will create social stories, visual schedules, and visual timekeepers that can be sued with the in individuals they support.

T-9 Exploring the Role of Spirituality and Disability

Facilitated by Kathy O'Connell, Bonnie Shoultz, Maureen Keyes, and Ron Taylor

This interactive workshop will explore various components of how spirituality can be an influential part of life for people living with disabilities. Specifically, this session will explore disability as a spiritual process, the power of meditation, imaging the future and spiritually centered leadership.

T-10 Civics 101...CANCELLED

T-11 Supported Living: It's Not a Program...It's Your Life!

Facilitated by Scott Shepard, Cheryl Mayfield, Keenan Inouye, Jose Perez, Pam Aiona, Carlos Cueva, Jill Martin, Igor Veremeykin, Ronda Michaelson, and Andre Vargas

A panel of people who receive services and support staff will share their stories about what supports they need and how those supports need to be provided to keep people

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TASH TECH Pre-Conference, Full-Day Workshops

Continued from page 8

safe and active in their communities. A brief overview of what Supported Living Services can and should provide will be discussed.

T-12 Creating and Sustaining Positive Partnerships with Paraeducators

Facilitated by Deborah Tweit-Hull, Ann Halvorsen, Pamela Villalobos, and Dona Meinders

Paraeducators play a pivotal role in many inclusive classrooms, yet there are few opportunities for professional development or training. This interactive workshop will present strategies and share materials developed to train, mentor, and evaluate paraeducators to provide effective supports in inclusive classrooms.

T-13 Perceptions of Spanish Speaking Families Regarding Inclusive Education in Southern California

Facilitated by Mary Falvey and Ben Adams

This workshop - to be presented in Spanish with interpreters - will present the views and perceptions of Spanish speaking families as they share their experiences with inclusive education in South-Central Los Angeles. Participants will look at the meanings and beliefs that led them to make the decision to educate their children, who have severe disabilities, in the general education classroom. Strategies in collaboration and problem solving will be shared.

T-14Transition as it Relates to the Young Person with a Disability

Facilitated by Marilyn Barraza and Susann Terry Gage

This workshop is designed to provide you with an awareness of transition as it relates to the young person with a disability and the opportunities that these life changes can provide. Participants will engage in developing meaningful transition plans for middle and high school students that will promote success in the post secondary setting. Each participant will draft a transition plan after defining what a quality life might look like for a young person with a disability. Multiple models of transition programs will be discussed.

T-15 Civil Rights, Self-Determination and Decision Making vs. Guardianship

Facilitated by Dohn Hoyle, Sally Burton-Hoyle, Kathleen Harris, Tom Nearney, and Mayer Shevin

Stripping people of their rights by establishing guardianship is altogether too common. This workshop will focus on alternatives and best practices for supporting people at risk, including individuals with the most significant decision-making support needs. Discussion will include how guardianship increases the risk for persons who are the most vulnerable, supporting choice and self-determination rather than substitute or "second party" best interest decision-making, as well as best practice in keeping with TASH values. This session is designed for family members, attorneys, care management, agency staff, and long-term advocates who believe in the principles of freedom and self-determination.

At the request of our members, TASH is trying something new this year. Institutes are full-day, interactive workshops that are available to conference attendees who register for the full three-day conference at no additional charge. Others are welcome to register and attend a full-day Institute as an "Institute Only" registration at the rate listed on the registration form on page 11.

Full Day Institutes

Saturday, November 17, 2001
10:00 a.m. - 4:00 p.m.

I-1 Critical Pedagogy and Inclusion: Understanding Our World in Order to Change It

Facilitated by Jacqueline Thousand and Don Cardinal, Suzanne Sooltoo, Ann Nevin, Rosario Diaz-Greenburg

Critical pedagogy explores the ways in which change is made in people's lives (all of our lives!). These ways don't necessarily fit with traditional parent/child, caregiver/service recipient, or teacher/student models of services. This session will encourage participants to challenge traditional ways of thinking about their roles as people with disabilities, staff members, parents, teachers, behavioral specialists, or other professionals and will encourage participants to rethink some of the most basic assumptions that have guided the field. Critical pedagogy suggest new ways of thinking and acting that will result in greater opportunities for mutually respectful relationships and social justice. Through dialogue we will address two questions. (1) How does understanding our world create the possibility of changing our experiences of the world we live in? (2) What do we need to understand about our world in order to change it? Join us for this exciting, interactive day.

I-2 Families Planning Together

Facilitated by Shelley Dumas, Mary Lou Bourne, Amanda George, Sherrie Anderson and Bonnie Miller

In this full day institute, families will learn a step by step process for beginning development of an "essential lifestyle plan" with their family members as well as to identify methods of obtaining on-going planning assistance. The plans created during this full day workshop will be used to help ensure the presence in life of what's important to and for family members.

I-3 Implementing Social Coaching

Facilitated by Paul Selby

Across the country, many individuals with significant support needs are now living and working in the "community". Yet, too often, their supports are provided following the old segregation policies and procedures. This full day institute will present strategies for social coaching in the community.

I-4 Cultural Brokering: Application of a Model to Provide Supports to Individuals and Families from Diverse Communities

Facilitated by Paula Sotnik

For a recent immigrant with disabilities, the challenge of obtaining supports is often arduous. The Cultural Brokering Model provides service providers with a replicable framework to develop effective support strategies by examining all factors in a sequential and participatory manner.

Continued on page 10

Saturday Institutes, Full-Day Workshops

Continued from page 9

Participants will apply the Cultural Brokering Model to analyze and better serve individuals with disabilities and families from diverse ethnic, linguistic and cultural backgrounds using presentation, small group and case study analysis application.

I-5 Supporting Students with Autism in General Education Classrooms: Lessons Learned

Facilitated by Rae Sonnenmeier and Michael McSheehan

Learn about New Hampshire's statewide system change efforts to support students with autism in general education classrooms. Examine the content covered in the varied training activities and the process for facilitating and sustaining change. Participate in skill building activities for professional and leadership development.

I-6 Stepping Out: A Game of Life that Goes to the Heart of What it Means to be Human

Facilitated by Sally Sehmsdorf, Chris Bily, Errin Bily and Sherry Lookabill

Stepping Out explores the Art of Dialogue, Person Centered Planning, and Diversity. Participants with and without disabilities collaborate to construct a game and play it. Imagine a giant board game with a path that begins with dreaming, moves through confusion to reflection, creates a space for calling a circle of friends, and finally reaches its goal of contribution to the community and full inclusion. Participants are encouraged to communicate their ideas using a variety of means.

I-7 Positive Behavior Support: Making It Work For Direct Support Professionals & Families

Facilitated by Scott Shepard

There has been a tremendous need in California to simplify curriculum related to PBS for the families and direct service staff who spend the most time directly supporting children and adults with behavioral challenges. Strategies will be shared for presenting and practicing information related to PBS with families and direct service staff to promote better understanding and success.

I-8 Core Curriculum for All: Strategies for Differentiated Instruction in Inclusive Classrooms

Facilitated by: Mary Falvey, Linda Lee, and Cindy Sawchuck

The morning portion of this workshop will provide information and technical assistance in providing differentiated instruction for students in inclusive settings. Through differentiated instruction, ALL learners will have access to the Core Curriculum. Strategies for adaptations and modifications will be explored to assist students' participation in the core curriculum. In the afternoon, a group of peer tutors from a middle school will present their program and discuss how they support students in inclusive settings.

I-9 (a) Going to School: Strategies for Parents to Build Communication Skills to Negotiate Their Childrens' Education (conducted in Spanish from 10 a.m. to 12:50 p.m.) (See description below.)

I-9 (b) Going to School: Strategies for Parents to Build Communication Skills to Negotiate Their Childrens' Education (conducted in English from 1:00 - 4:00 p.m.)

Facilitated by Barbara Marbach, Ron Lopez and Dale Mentik

Representatives of the Class Member Review Committee and their counsel, Protection & Advocacy, present a report on the status of the Chanda Smith Consent Decree, now in its fifth and most crucial year to date. The Committee's new documentary "Going to School" by Richard Cohen Fils.com will be screened with English/Spanish subtitles. It provides a first-hand look at inclusion and special education services by focusing on a Los Angeles middle school. Using this film as a tool, this session will explore strategies for building essential collaboration skills so parents can better negotiate for their child's special education services and become effective collaborators with their school team.

I-10 An Introduction to "Real Futures: A Transition Training for Parents of Children with Disabilities"

Facilitated by Mary Cazden and Wendy Byrnes

Parents, educators, and agency staff will be introduced to "Real Futures: A Parent Transition Training" designed to empower families to advocate and enable their children to transition to a full and integrated community life. Modules include: laws and regulations; person-centered planning; benefits; social and psychological dynamics within the family; model living and employment programs; health care issues; socialization; and IEPs.

I-11 Inclusive Secondary Schools -- Lessons Learned in Supporting Diverse Students

Facilitated by Doug Fisher

This session focuses on creating inclusive schools for students at the middle and high school level. Discussion of topics such as differentiating instruction for all students, curriculum modifications and accommodations, and individualized supports.

DIRECTOR OF CONNECTIONS

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Registration Category – Current TASH International Members			
[ ]	Individual Registrant	**$239**	Current TASH Member # ____________ (*Personal assistants must register at the same time as individual for whom they are providing support to attend conference activities)*
[ ]	Family Member / Or Person with a Disability	**$ 79**	
[ ]	Personal Assistant *	**$ 50**	
[ ]	Student	**$ 159**	
[ ]	One day only ☐Thurs ☐ Fri	**$149**	

Registration Category – TASH Chapter Only or Non-Members			**Register and JOIN International TASH NOW!!**
[ ]	Individual Registrant	**$369**	$327
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[ ]	One day only ☐Thurs ☐ Fri	**$199**	$237

1. Enter Registration Cost	**To join your chapter also please add $15.00**	$ ____________

Additional Registration Discounts

A. Team Discounts - Groups of 5 or more registering together **(must be in the same envelope)** **B. Early Bird** - registrations received before **Sept. 17, 2001**	**Subtract Discount Here →** $20.00 per person, per discount	$ -____________
Round Table Networking Luncheon – Thursday, 1:00-2:15 PM *(you must purchase a ticket in advance, and please be sure to note any special diet requests)*	$20.00 per person **Add Luncheon Fee Here →**	$ ____________

Pre-Conference Workshops 1:00 - 6:00 PM, Wednesday, November 14th ***(Registration is in addition to the conference fees)*** **Saturday Institutes, 10:00 AM - 4:00 PM November 17th (If you registered for the Full conference you can attend one of the Saturday Institutes at no charge. If you would like to sign up to attend an Institute ONLY - the rates below apply.**

Please review the TASH TECH Workshops and Institute descriptions on pages 8-9. Be sure to mark the number of your first and second choices.
○ I plan to attend the Saturday Joint Strategic Planning Session (no charge)
○ I plan to attend a TASH TECH 1st Choice _____ 2nd Choice_____
○ I plan to attend a Saturday Institute 1st Choice _____ 2nd Choice_____
Enter Total Additional Fee Here →

Rates for TECHS **and** Institutes:

• TASH Member	$55.00
• Non-Member	$85.00
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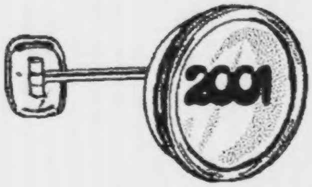
Registration will not be accepted without payment by check, purchase order, or credit card authorization. Payment must be in U.S. Funds only. A $25.00 fee will be deducted from all requests for refunds received before October 15, 2001. No refunds after that date. $25.00 fee for returned checks or unauthorized charges.



In Focus Areas

Advocacy

Thursday and Friday
Coordinator: Dan Dotson

Join this lively focus area for a series of presentations on advocacy and self-advocacy. Sessions will be facilitated by advocates and self-advocates and will focus on the skills needed to effect change at both the personal and policy levels. All sessions within this focus area will provide opportunities for discussing ideas and for sharing strategies for success.

Alternate Assessment

Thursday and Friday
Coordinator: Donna Lehr

The IDEA 97 requirement that all students participate in state-wide systems of assessment has required much work in each state on the design of alternate methods of assessment appropriate for students with severe disabilities. This focus area features sessions that explore the common issues and specific practices established in individual states aimed assuring that students with severe disabilities are a part of state accountability systems.

Community Living

Thursday and Friday
Coordinators: Joe Wykowski and Patti Scott

A diverse group of individuals and agencies will share their stories and perspectives concerning how to live a rich community life using individual support strategies, friendships, and the acquisition of affordable, accessible housing.

Critical Pedagogy and Inclusion

Thursday and Friday
Coordinators: Don Cardinal and Jacque Thousand

Critical pedagogy explores the ways in which change is made in people's lives. These ways don't necessarily fit with traditional parent/child, caregiver/service recipient, or teacher/student models of services. This focus area will feature sessions that encourage participants to challenge traditional ways of thinking about their roles and encourage them to rethink some of the most basic assumptions that have guided the field.

Early Childhood

Thursday and Friday
Coordinator: Elizabeth Erwin

This focus area includes a variety of sessions that highlight compelling issues and innovative practices regarding inclusive early education for young children with significant disabilities and their families.

Employment

Thursday and Friday
Coordinator: John Butterworth

Opening with an issues forum, the employment focus area will highlight policy developments, organizational change strategies, and emerging support practices that expand access to high quality careers. Join us for the Thursday Issues Forum and Luncheon Roundtable to define issues and strategies.

Family

Thursday - Saturday
Coordinator: Ann Turnbull

This focus area includes a variety of topics that are especially relevant to families and professionals who support families. All sessions included in this focus area are facilitated by at least one family member.

Focus on Government Affairs: Training Effective Advocates

Thursday
Coordinators: Liz Obermayer and Jamie Ruppman

A series of workshops, panel presentations and activities that will help us all become more confident and effective advocates for ourselves and others. Participants will find that these sessions are welcoming to everyone and accessible to everyone. If you are new to advocacy, shy about speaking up or writing letters and sometimes confused about who to talk to and about what, these activities are for you! Experienced advocates will learn new strategies and share ideas with a diverse group of national leaders.

Forging New Alliances in School Reform: Roles of Related Services for Successful, Inclusive Communication and Literacy Support

Friday
Coordinator: Michael McSheehan

While most students with labels of severe disabilities receive related services as part of their IEP, those supports are not typically planned to be nor are they provided in the general education classroom. Come learn about the changing roles of related service providers in supporting successful inclusion within the contest of school reform. These interactive sessions will address promising practices of related service providers in designing the communication and literacy supports for a student's meaningful engagement in general curriculum.

Guardianship Alternatives: Melding TASH Values with Best Practice

Friday
Coordinator: Dohn Hoyle

This focus area includes sessions that discuss guardianship as the last civil rights frontier, an exploration of strategies for self-determination, issues related to wills and trusts, and practices in alternatives to legal guardianship will be discussed.

Inclusion Works

Friday
Coordinator: Nancy Frey

Woodrow Wilson said, "I can't tell you the right way to do the wrong thing."

Continued on page 13

2001 In-Focus Areas

Continued from page 12

While practices labeled "inclusion" are common, some are missing necessary elements. This focus area will examine what we know about successful inclusive practices, and the important aspects that insure successful experiences for students, teachers, and families.

Innovative Transition Practices for Achieving Typical Adult Life Styles

Thursday - Saturday

Coordinator: Pat Rogan

This focus area provides an array of exciting sessions that address positive approaches for transition from school to adult life. Session topics include student-centered planning approaches, innovative options for preparation for adult lives, post-secondary education opportunities, and collaboration with adult services and supports.

Literacy

Thursday

Coordinators: Leonore Pelligrino-Sino and Amy Staples

Literacy is a critical life skill. The past decade has marked a shift in research, practice, and learning. This focus area will offer participants the opportunity to become familiar with current research, best practices, and outcomes related to literacy instruction for all learners.

Media, Meditation and Mediation: How Spirit Manifests in Everyday Life

Thursday

Coordinator: Maureen Keyes

How do we manifest spirituality through communication and relationship? Everyone is welcome to join this focus area to learn about and share personal experiences of spirituality from our participation in families, communities, faith-based organizations, work places, schools and centers of entertainment and rejuvenation.

Multicultural: Including Culturally and Linguistically Diverse Individuals and Families

Thursday and Friday

Coordinator: Susie Schaefer

The focus on ethnicity and cultural competency is necessary and appropriate in today's world. Sessions will offer information, discussion and sharing about issues faced by those seeking and needing assistance and those interested in being responsive and inclusive. This focus area will offer an opportunity for a diverse group of individuals to meet formally and informally.

Not Dead Yet – Navigating the Slippery Slope

Thursday

Coordinator: Stephen Drake

Not Dead Yet organizes the disability community's opposition to legalized assisted suicide/euthanasia. Every session in this focus area will give information on current threats to the lives of people with disabilities and ways to organize and resist the assisted suicide/euthanasia movement.

Paraeducator Issues

Thursday

Coordinator: Patricia Mueller

Topics in this focus area will address the following issues related to paraeducators: schoolwide planning; attributes of outstanding paraeducators; what administrators need to know about hiring and supporting these staff, training, and "hot topics" in the field of "paraeducation".

Preparing Personnel for Inclusive Schools

Thursday - Saturday

Coordinator: Lewis Jackson

Teacher preparation in the age of inclusion requires re-thinking University curriculum. Presentations in this focus area will offer practical strategies for this process.

Positive Approaches to Supporting People with Complex Needs and/or Problem Behavior

Thursday and Friday

Coordinators: Rob O'Neill and Tim Knoster

This focus area includes presentations that focus on concepts, principles, and strategies for implementing positive, and, support approaches in school, home, and community settings.

Postsecondary Education: Same Questions, New Setting

Thursday

Coordinator: Caren Sax

As more students graduate from inclusive high schools, many are eager to continue their education at the postsecondary level. But the same questions remain: how to access supports; which provides and pays for the services; how to best access different classes and professors; how to learn about the new system. Join us for a day of exploring questions, experiences, successful strategies, and remaining challenges as we move into the next education frontier. Students, families, educators, and other professionals will have much to learn as well as to share with those who are blazing yet another new trail.

Removing the Barriers to Full Inclusion

Thursday

Coordinator: Cheryl Jorgensen

Why is the realization of "full inclusion" so difficult when we know its benefits? This focus area will take a hard look at the barriers to inclusion — some of which we create ourselves — and offer strategies for addressing them.

Research

Thursday and Friday

Coordinator: Linda Bambara

This focus area features sessions on quality of life issues (e.g. inclusion, quality assurance and measurement, friendships, new roles of support staff) in schools and communities.

Continued on page 14

2001 In-Focus Areas

Continued from page 13

School Based Professional Development: More Powerful Teaching

Friday

Coordinators: Janice Payne and Charles Fitzgerald

Professional development is seen as one of the key factors in successful school change and restructuring, improved outcomes for all students and access to inclusive options for individuals with diverse learning styles and abilities. We will explore different successful models of school based professional development and success implications for training and retaining the best and brightest to teach our children and youths. Join this focus area as we continue to learn together.

School-wide Positive Behavior Support

Friday

Coordinator: Rob Horner

This strand will include five sessions addressing current practices and recent results from schools across the country that are working on implementing positive behavior support throughout the whole school. Rob Horner, Wayne Sailor, Lisa Cushing, Rick Albin and Tim Knoster will each present 1-hour sessions that address strategies for making schools more behaviorally inclusive. Specific topics will include the challenges faced by urban schools, the development of positive school-wide social cultures, designing function-based support for individual children, and policy challenges for the future.

Seeking to Understand Autism in Different Ways

Thursday and Friday

Coordinator: Jeff Strully

This focus area is meant to provide a deepening of our understanding of autism from many different perspectives. This is not a series on "how to" , but rather an opportunity to explore, understand, seek new information and to be challenged. Everyone is welcome, especially those who live with and support people with autism in valued ways.

Self Determination

Thursday and Friday

Coordinator: Charles Moseley

State systems of support for people with developmental disabilities are changing to incorporate principles of self-determination at both policy and operational levels. This transformation requires significant modifications in the structure and functioning of existing programs to enable people receiving support to take control over the financial and support related decisions that affect their lives. This focus area will discuss implementation from the perspectives of individuals from different states who are involved in the process of change. The presentation will identify challenges faced by states making the change to person-centered, individually controlled systems of support; management and administrative actions that facilitate the change process, and barriers that must be removed.

Sexuality

Thursday and Friday

Coordinator: Wanda Blanchett

Sexuality and sexual expression are natural parts of each of our lives. For many individuals with significant disabilities, access t complete and accurate information regarding issues of sexuality is not readily available. To ensure that the sexual rights of individuals with disabilities are acknowledged and respected, these sensitive and critical issues require awareness, respect, and a commitment to ensure all people have the information needed to act upon their interests, preferences, and choices.

Strategies for Providing Inclusion Support for Young Children with Intensive/Specific Needs

Friday

Coordinator: Brigitte Ammons

This focus area will provide sessions that offer specific strategies and techniques for including and supporting young children with significant disabilities in inclusive settings. Parents and professionals are welcome as we discuss the barriers to inclusion and strategies for overcoming them.

Urban Issues

Friday

Coordinator: Elizabeth Kozleski

The National Institute for Urban School Improvement is hosting this year's urban focus area. We hope that you will join us in conversations around systemic change, family involvement, policy development, and strategies for practice improvement at the classroom and building level. We have invited a group of practitioners, administrators and researchers to join us in this exploration. Please drop in during the day and be part of the discussion of lessons learned in large, multi-cultural, complex school systems.

Voices of Friendship

Friday

Coordinators: Carol Tashie, Zach Rossetti, and Jeff Strully

This all-day focus area is designed to pose the question and explore the attitudinal and educational barriers to friendship that continue to exist, even in schools that include students with disabilities in general education classes. Strategies to avoid and overcome the barriers, as well as approaches to facilitate meaningful relationships between students with and without disabilities, will be discussed.

Look for additional focus areas on the following topics: Ethics and Rights, Creative and Performing Arts, and Special Health Care Needs.

2001 TASH CONFERENCE BREAKOUT SESSIONS

Thursday, November 15

10:30 am — 11:30 am

Living Free: Campaign for Freedom
Topic Area: Advocacy
Speakers: Michael Taylor, Elizabeth Obermayer, Dan Dotson, Tracy Wright, Phil Weintraub, Judy Volkman

Listening to the Experts
Topic Area: Autism
Speakers: Robert Cutler, Susan Rubin, Peyton Goddard, S. Hap Hinkle

A Year Later
Topic Area: College
Speakers: Caren Sax, Jeffrey L. Strully

Our First Ten Years of Facilitated Communication: Close Encounters After Twenty Years
Topic Area: Communication
Speakers: David Marcus, Eugene Marcus

Opening Doors to the Community Through The Use of Augmentative Devices
Topic Area: Community Living / Communication
Speaker: Cynthia Hennessy

You Have Questions? So Do We! Practical Problem Solving Approaches for Anyone Interested in Supporting Meaningful Lives
Topic Area: Community Living / Housing / Self-Determination
Speakers: James Meehan, Gail Fanjoy, Sally Sweeney

Emerging Directions in Early Childhood Inclusion Research
Topic Area: Early Childhood/Research
Speakers: Elizabeth Erwin, Leslie C. Soodak, Georgia Atkins

Killing Without Consent I - The Cases of Tina Cartrette and Robert Wendland
Topic Area: Euthanasia Resistance
Speaker: Vincent Fortenasce, Stephen Drake

Parent Transformational Outcomes When a Child has a Disability: Parent Reports and Research Findings
Topic Area: Family
Speakers: Lorraine Wilgosh, Kate Scorgie, Richard Sobsey

From the Inside Out; Creating Supports for Families
Topic Area: Family
Speakers: Kathy Ballard, Lisa Steward

Assessing the General Curriculum Through Adaptations and Assistive Technology or "How Am I Going to Teach THAT?"
Topic Area: General Curriculum Access /Assessment Technology
Speakers: Michael Burdge, Anne Denham, Jean Clayton

First Things First!
Topic Area: Governmental Affairs
Speakers: Elizabeth Obermayer, Jacqueline Golden

"We're Hangin' 'Em out to Fail?": The Impact of Standards-Based Reforms on Special Education and Student with Disabilities
Topic Area: High School Inclusion/ Special Ed Policy
Speaker: Bud Cooney

Real and Perceived Inclusion in Schools: Dark Ages or Bright Future?
Topic Area: Inclusive Education/ Urban Education
Speaker: Susan Turben

Collaborative, Consultation, Collaborative Results: Stories from Teaching Teams
Topic Area: Inclusive Education/ Personnel Preparation
Speakers: Gwen Beegle, Megan S. Cote, Susan Bashinski, Joe Porting, Donna R. Wickham, Ruthie Mendocinos

Collaborative Teaming to Support Students With and Without Disabilities in General Education Classrooms
Topic Area: Inclusive Education
Speakers: Pamela Hunt, Anne C. Smith

Systematic Reading Instruction for Diverse Learners
Topic Area: Literacy
Speakers: Jennifer Butterworth, Sheri Keel

A Guide to Schoolwide Planning for Paraeducator Supports: A Pilot Study
Topic Area: Paraprofessional
Speaker: Michael F. Giangreco

Inclusive Teacher Preparation: Ensuring Success for ALL
Topic Area: Personnel Preparation
Speakers: Susan Leonard-Giesen, Marquita Grenot-Scheyer

The Effects of Functional Assessment Information on the Behavioral Support Recommendation
Topic Area: Positive Approaches
Speaker: Richard Albin

Tearing Down the Barriers to Full Inclusion: Beginning with Ourselves
Topic Area: Removing Barriers to Full Inclusion
Speaker: Jeffrey L. Strully

Teaching Support Staff to be Responsive Listeners to Facilitate Self-Determination
Topic Area: Research/Self-Determination
Speakers: Freya Koger, Linda Bambara

Preparing Students with Significant Disabilities for Healthy Sexual Lives
Topic Area: Sexuality
Speakers: Wanda J. Blanchett, Pamela Wolfe

Continued on page 16

THURSDAY SESSIONS

Continued from page 15

Science Groups: Creating Space for All Students
Topic Area: Social Justice / Research
Speakers: Mary Fisher, Sara McGrew

S.R.I. (Somato Respiratory Integration)
Topic Area: Spirituality
Speaker: Beth Lakretz

Families and the Transition Process
Topic Area: Transition / Family
Speakers: Barbara Buswell, Elisabeth Healey

Thursday, November 15

10:30 am — 12:45 pm

Understanding the Relationship between the Oppressed and the Oppressor
Topic Area: Critical Pedagogy
Speaker: Suzanne SooHoo

Employment Issues Forum
Topic Area: Employment
Speakers: John Butterworth, Michael Callahan

"Getting a Life" for Adults through Individualized Funding and Self-Determination
Topic Area: Family/Self-Determination
Speakers: Charles Moseley, Ann Turnbull, Doug Gragson

Resources and Best Practices for Reaching and Serving Culturally and Linguistically Diverse Families
Topic Area: Multicultural
Speakers: Betsy Santelli, Theresa Cooper, Sweet Alice Harris

Thursday, November 15

11:45 am — 12:45 pm

Developing a Peer Counseling for People with Developmental Disabilities
Topic Area: Advocacy
Speakers: Joe Meadours

WeBCATT: We Build Communication Access Through Technology
Topic Area: Assistive Technology
Speakers: Sandra Alper, Charlotte Mull, Delann Soenksen

Listening to Families
Topic Area: Autism / Family
Speakers: Barbara Cutler, Connie Lapin

Quiet Advocacy and the Acquisition of AAC for Culturally Diverse Families: A Case Study
Topic Area: Communication/ Multicultural
Speaker: Shannon McCord

Community Member Forums: Empowering Community Members' Accountability for Full Community Inclusion
Topic Area: Community Living/ Housing
Speakers: Angela Novak Amado, Jackie Victorian-Blaney

Supported Living; Supporting Choices in Living
Topic Area: Community Living/ Housing
Speakers: Laurie Snyder, Joanne Cain, Waltina Mansolillo, Carla Tankard

Transition Across Early Intervention Contexts: Family Challenges and Professional Practice Issues
Topic Area: Early Childhood / Family
Speakers: Crystal Ladwig, Melinda Morrison

Killing Without Consent II - Tracy Latimer and Others - and How Their Murders are Exploited by Pro-Euthanasia Groups
Topic Area: Euthanasia Resistance
Speakers: Dick Sobsey

Planning for the Future of Your Special Needs Child
Topic Area: Family/Financial Planning
Speakers: Nadine Vogel

Person Centered IEP Planning: Promoting Self-Determination for Parents and Students
Topic Area: Family
Speakers: Amy Lynn Childre, Cynthia Chambers

Things that Worked and Things that Didn't
Topic Area: Governmental Affairs
Speakers: Robert Sneirson, Bill Coffelt

Linking Standards-Based Instruction and Authentic Performance Assessment
Topic Area: Inclusive Education / Assessment
Speakers: Mariel Zeller, Jacqueline Farmer Kearns, Michael Burdge

Strategies for Collaborating to Differentiating Instruction
Topic Area: Inclusive Education/ Collaboration
Speakers: Melanie Hammond Christian, Melissa A. Brown

Inclusion Teacher Survival 101: A Resource-Abundant Workshop for Novice Inclusion Teachers
Topic Area: Inclusive Education/ Teacher Preparation
Speakers: Shawna Olson, Amy Hanreddy

Families Speak Up
Topic Area: Inclusive Education / College
Speakers: Barbara McKenzie, Candee Basford, Katie Basford

Teaching Literacy Skills to Students with Severe Disabilities in General Education Classrooms
Topic Area: Literacy
Speaker: June Downing

Continued on page 17

THURSDAY SESSIONS

Continued from page 16

French Fries or Friendship Facilitation: Which Paraeducator Characteristics are Valued by Schools?
Topic Area: Paraprofessional/Qualitative Research
Speaker: Deborah P. Goessling

Bridging the Gap Between Best Practice and Current Practice: Preservice Teacher Preparation in the Age of Inclusion
Topic Area: Personnel Preparation
Speakers: Heather C. Young, Barbara Gruber

Positive Behavior Support and the Family: Research Outcomes and Social Validation
Topic Area: Positive Approaches/ Research
Speakers: Mendy Boettcher, Erin McNerney, Lisa Fan, Rachel Fan; Robert Fan, Robert Koegel, Lynn Kern Koegel

Tearing Down the Barriers to Full Inclusion: Low Expectations and the Myth of Mental Retardation
Topic Area: Removing Barriers to Full Inclusion/Inclusive Education
Speaker: Zachary Rossetti

Facilitating Social Interaction of Adults with Developmental Disabilities in the Community
Topic Area: Research / Staff Training/ Adult
Speakers: Ophelia N. Gomez, Linda Bambara

Relationships, Friendships, and the Community: Person-Directed Planning as a Guide for Full Participation
Topic Area: Self-Determination/ Creative/Performing Arts
Speakers: Paula Bohland, Robin Dean

Disability Studies: What It Means for Inclusive Education
Topic Area: Social Justice / Inclusive Education
Speaker: Philip R. Smith

Professional Renewal in Spiritually Centered Leaders for Justice and Equity
Topic Area: Spirituality / Inclusive Education
Speakers: Maureen Keyes, Ron Taylor

Working Towards Independence: Strategies for Releasing the Grip
Topic Area: Teacher Development / Inclusive Education
Speakers: Margaret Stout, Sara Egorin-Hooper

Transition Service Integration Model: Integrating Public Schools, Rehabilitation and Developmental Disability System to Produce a Seamless Transition
Topic Area: Transition
Speakers: Nicholas J. Certo, David Noyes, Caren Sax, Denise Mautz, Holly Wade, Kimberley Smalley, Richard G. Luecking

Thursday, November 15

2:15 pm — 3:15 pm

YouthSpeak: Taking Charge, Changing Images!
Topic Area: Advocacy
Speakers: Deborah A. Gilmer, Janet May, Bonnie Robinson, Elijah Steward

Let's Talk Partners
Topic Area: Advocacy
Speakers: Michael Bailey, Catriona Johnson

Inclusive Strategies Using Assistive Technology: Bringing AT into Regular Education Curriculum
Topic Area: Assistive Technology
Speakers: Debra Bauder, Deb Case, Thomas J. Simmons

Ethics and Values of Behavior Change
Topic Area: Autism/Ethics
Speaker: Larry Douglass

Imaging Inclusive Education for Students with Autism: "We Have to Start with Inclusion and Work it Out As We Go"
Topic Area: Autism
Speakers: Christi Hendrickson, Alicia Broderick

Creating Access to Postsecondary Education for All Youth
Topic Area: College/Postsecondary Education
Speakers: Debra Hart, Karen Zimbrich

Inclusive Recreation and Leisure for Youth
Topic Area: Community Living/ Housing
Speakers: Esther Onaga, Steve Youngblood

Come Play With Me: Strategies that Work for Young Children who are Deaf-Blind
Topic Area: Early Childhood / Family
Speakers: Melinda Morrison, Crystal Ladwig

What is the Natural Supports Research Telling Us About How We Provide Employment Services and Improve Employment Outcomes?
Topic Area: Employment
Speaker: Teresa A. Grossi

Coalitions - Natural and Unnatural Allies in Fighting the Assisted Suicide/Euthanasia Movement
Topic Area: Euthanasia Resistance
Speakers: Lillibeth Navarro, Michael Bailey

Beat the Clock: Enhancing Your Child's Quality of Life While Knowing that Death May Be Imminent
Topic Area: Family
Speakers: Tricia Luker, Calvin Luker

Inclusion in School is Always Good for Everyone
Topic Area: High School Inclusion
Speakers: Kevin Wagner, Anita Wagner

Continued on page 19

THE EDUCATION CORNER

If you have a child with a disability and you want more information on special education laws and services, or if you are a professional who works with families of children with disabilities or those having difficulty in school and you want to learn more about special education, the Families and Advocates Partnership for Education (FAPE) can help. FAPE is a national project which informs families and advocates about the Individuals with Disabilities Education Act of 1997 (IDEA '97).

A major goal of this law is to improve educational results for children with disabilities and to make sure that schools focus on high expectations for these children. In order for children with disabilities to reach their full potential, it is important for parents to learn about changes to the law and how the changes will affect their children. How can FAPE help? FAPE provides:

- ❖written information about IDEA '97
- ❖ technical assistance on IDEA '97.

Parents may have questions answered by calling toll-free 1-888-248-0822 or by sending an e-mail to FAPE@pacer.org.

- ❖Web site (www.fape.org) with information about IDEA '97, including Spanish and Hmong translations of some materials
- ❖referrals to national, state, and local disability organizations and advocates
- ❖referrals to a nationwide network of parent training and information centers and community parent resource centers.

Are you looking for comprehensive staff development options?

LRConsulting offers resources for administrators, teachers, paraeducators, assessment personnel, and parents.

©Triplicity - an administrator's guide to mentoring paraeducators

©Paraeducators: LifeLines in the Classroom - six training modules for new and returning paraeducators

©Melding - a training module and guide for partner teachers working with paraeducators

©Maxim - a guide for linking functional-contextual assessment to instruction

©Students First - a training module for parents as partners in the Special Education process

Visit our web site or call to learn more about ordering materials, our training-of-trainers workshops, and hosting a TOT in your district.

www.lrconsulting.com

LRConsulting

PMB 747 POB 6049
Katy, TX 77491-6049
PH: 281-395-4978
Fax: 281-392-8379

THURSDAY SESSIONS

Continued from page 17

Empowering Peers to Image Their Future: Student Leadership and Peer Tutor Training in Secondary Schools
Topic Area: High School Inclusion
Speakers: Pam Villalobos, Lori Eshilian, Deborah L. Tweit-Hull

Service Learning: Maximizing Inclusive Opportunities
Topic Area: Inclusive Education
Speakers: Cynthia Chambers, Amy Lynn Childre

Hey, Why Weren't You at the Gym!!
Topic Area: Leisure and Recreation/ Self-Advocacy
Speakers: Michael Shanzer, Beth Shanzer

The Honoring of Diversity in Reading Instruction
Topic Area: Literacy Strand
Speakers: Christle Ranelle, Elizabeth Willis

Principal's Paraeducator Priorities
Topic Area: Paraprofessional
Speakers: Mary Lasater, Marlene Johnson

Reaching Rural Areas: Field-Based Teacher Preparation
Topic Area: Personnel Preparation/ Teacher Preparation
Speaker: Mary Beth Doyle

Practical Strategies to Address Problem Behaviors
Topic Area: Positive Approaches
Speakers: Vivian M. Perez-Kennedy, Kathryn D. Peckham-Hardin

Tearing Down the Barriers to Full Inclusion: The Effects of 'Pull-Out' on Community and Learning
Topic Area: Removing the Barriers to Full Inclusion
Speaker: Carol Tashie

Death in California? Life Outcomes for 2,300 Coffelt Movers from Institutions in California
Topic Area: Research/Community Living
Speakers: James W. Conroy, Mary Hayden, Jefferey X. Seiders

Teaching Self-Determination Via Vocational Choice Making
Topic Area: Self-Determination / Employment
Speaker: James Martin

Exploring Media: Spiritually Uplifting Insights from Contemporary Film and Television While Sharing the Epiphanies of Parenting and Educating Children with Disabilities
Topic Area: Spirituality/Media
Speakers: Ron Taylor, Maureen Keyes

Access to General Education Curriculum in Iowa: The Battle of Local Control
Topic Area: Statewide Alternate Assessment
Speakers: Kathy Davis, Sandra Alper, Martin Agran, Mike Cavin

Providing Community Based Transition Services for Students 18-22
Topic Area: Transition / Self-Determination
Speakers: Eileen Medina, Judy Dobbins, Marylynne Shields, Duanne Turner, Alex Geffken

Thursday, November 15

2:15 pm — 4:30 pm

Real Life Self Determination
Topic Area: Community Living / Self-Determination
Speakers: Joe H. Wykowski, Patti Scott

Taking Action
Topic Area: Governmental Affairs
Speakers: Jamie Ruppmann, Bonnie H. Shoultz

Community Building in Your Diverse Classroom: Creating Healthy, Inclusive Environments in Elementary Schools
Topic Area: Inclusive Education / Friendship
Speakers: Kristen Goldmansour, Beth Lakretz, Kim Conger, Diane Ripple

Connecting Families of Diverse Cultures to Inclusive Education
Topic Area: Multicultural
Speaker: Ginette Goldfeld

Teaching About Best Practices
Topic Area: Personnel Preparation
Speakers: Keith Storey, Sandra Alper, Diane Browder, Janis Chadsey, June Downing, Carolyn Hughes, Donna Lehr

The Elusive Nature of Social and Sexual Intimacy for Young Adults with Significant Disabilities
Topic Area: Sexuality/Sexual Expression
Speakers: Holly Wade, Shelly Rodgers, Nicholas J. Certo

Thursday, November 15

3:30 pm — 4:30 pm

The California Community Imperative "A Turning Point" Conference
Topic Area: Advocacy
Speakers: Bill Coffelt, Terry Boisot, Mark Polit, Bonnie H. Shoultz

When the World Wide Web Wasn't (And Largely Still Isn't)
Topic Area: Assistive Technology
Speakers: Eric Chapman, Alan Parks

An Evaluation of Life Satisfaction from the Perspective of Individuals Receiving Supported Living Services and Their Significant Others
Topic Area: Community Living/ Housing
Speakers: Maryam Abedi, Kathryn Edwards, Lori Leak

Continued on page 21

2001 TASH CONFERENCE EXHIBITS

The TASH Conference promises to be *the* place to host over 2,200 of your customers! Each exhibitor will receive three conference registrations, a complete booth package, TASH discounted hotel and airline rates, and the opportunity to capture an audience interested in the innovative services, products, and information available to assist people with disabilities. And don't forget this value-added feature available to TASH exhibitors: your company name, booth number, and a list of up to five products or services on TASH's web site at no extra cost!

Plan to join us in the Exhibit Hall for the Thursday evening reception honoring the TASH Positive Images Awards winners. The Exhibit Hall will be filled with exhibits of the products, publications, and services TASH conference attendees are looking for. Another special event scheduled for the Exhibit Hall is a silent auction, hosted by Cal-TASH, on Friday evening.

We welcome back many vendors familiar to our attendees, and we are pleased to have many newcomers joining us in Anaheim. Plan to do some early holiday shopping with us!

Some of the many exhibitors to be seen at the 2001 TASH conference include:

- Adrian's Closet
- APSE
- Aurora Ministries
- Brookes Publishing
- Canine Companions for Independence
- Capacity Works
- Center on Human Policy
- Community Partnerships, Inc.
- Disability is Natural
- Discovery Toys
- DynaVox Systems
- Greenhouse Publications
- Peak Parent Center
- Social Security Administration
- Super Duper Publications
- Trips Inc.
- The Nth Degree

Added exhibit features to maximize traffic in the Exhibit Hall:

- *Exclusive* exhibits-only time during the conference
- Thursday evening reception honoring the TASH Positive Images Awards winners
- Conference Registration and Information areas located just outside of the Exhibit Hall
- Continental breakfast during the Saturday morning exhibits and poster sessions

Exhibit Schedule

- Exhibit Set-Up:
  Thursday, November 15, 2001
  7:00 AM - 10:00 AM

- Exhibit Hours:
  Thursday, November 15, 2001
  10:00 AM - 1:00 PM
  2:30 PM - 6:00 PM

  Friday, November 16, 2001
  8:00 AM - 10:30 AM
  1:30 PM - 7:30 PM

  Saturday, November 17, 2001
  8:00 AM - 12:00 PM

- **Exhibit Breakdown**:
  Saturday, November 17, 2001
  12:00 PM - 3:00 PM

Increase active participation

To obtain an exhibitor application or for more information contact Rose Holsey at 1-800-482-8274, ext. 100 or send an e-mail to rholsey@tash.org

THURSDAY SESSIONS

Continued from page 19

Stewarding One's Own Path to Employment
Topic Area: Employment/Self-Determination
Speaker: Marsha Threlkeld

Media and Politics - Meaning, Money, and the "Right" to be Killed
Topic Area: Euthanasia Resistance
Speaker: Cyndi Jones, Stephen Drake

Parent to Parent: A Resource for Families and Professional
Topic Area: Family
Speakers: Betsy Santelli, Florene Poyadue

Practical Strategies for Adapting Curriculum within the Inclusive Classroom
Topic Area: Inclusive Education
Speakers: Karen Warne, Monica Agpaoa-Gonzales

Use of Alternative Assessment to Facilitate Inclusive Options for Students with Severe Disabilities
Topic Area: Inclusive Education/Assessment
Speakers: Kathryn D. Peckham-Hardin, Margo M. Yunker

Creating Inclusive Summer Programs for Children that Educate Children About Diversity
Topic Area: Inclusive Education
Speakers: Karena Cooper-Duffy, Kathy Blossfield, Dianne Prohn

Postsecondary Opportunities for Individuals with Disabilities: A Dialogue Between Program Based and Individual Support Models of Services
Topic Area: Inclusive Education/College
Speakers: Meg Grigal, Cate Weir, Debra Neubert

Crackerbarrel: Paraeducator Special Interest Group
Topic Area: Paraprofessional
Speaker: Patricia H. Mueller

Collaborative Community Partnership
Topic Area: Positive Approaches/Advocacy
Speakers: Jill Broadbent, Sharen Bowen, Lynne Patterson

Determining Approaches Psychiatric Supports for Adults with Significant Cognitive and Physical
Topic Area: Related Services
Speaker: Lori Noto

Tearing Down the Barriers to Full Inclusion: Communication Supports for Inclusion That Works Before We "Know What They Know"
Topic Area: Removing the Barriers to Full Inclusion
Speaker: Rae Sonnenmeier

Meeting the Needs of Children with Autism Spectrum Disorders: How Well Are We Doing?
Topic Area: Research / Autism
Speaker: Stacy Dymond

Helping Students Find Their Voice: Teaching Self-Determination in a Rural High School
Topic Area: Self-Determination/High School
Speakers: Vicky Piland, Bruce M. Menchetti

Exploring the Components of Spirituality & Disability
Topic Area: Spirituality
Speakers: Kathryn O'Connell, Bonnie H. Shoultz, Maureen Keyes, Ron Taylor

Supporting A First Year Teachers Journey Toward Enacting Accessible Curriculum
Topic Area: Teacher Development
Speakers: Shoshana Reiss, Britt K. Hamre

School to Adult Life: Alma's Story
Topic Area: Transition
Speakers: Rachel Quenemoen, Alma Quenemoen, Sandra Thompson

Thursday, November 15

3:30 pm — 5:45 pm

Supporting People to Live Real Lives
Topic Area: Autism
Speakers: Dorothy Farrell, Laura Broderick, Cindy Strully, Jennifer Lengyel

Communication Services and Supports for Persons with Severe Disabilities
Topic Area: Communication
Speakers: Martha Snell, Pat Mirenda

The Criminal Justice System and You: An Introduction for Self-Advocates
Topic Area: Criminal Justice / Advocacy
Speakers: Alan Kurtz, Helen Bailey, Alan Hammond, Lenny Berry, Kathy Son

Realize the Possibilities: Inclusion Advocacy Strategies for Families
Topic Area: Inclusive Education/Family
Speaker: Beth Schaffner

The Orange County Full Inclusive Preschool Project
Topic Area: Inclusive Education / Early Childhood
Speakers: Jan S. Weiner, Abby Rozenberg, Catherine Titus, Lara Hunter

Thursday, November 15

4:45 pm — 5:45 pm

United We Stand, Together We Get Nowhere
Topic Area: Advocacy
Speakers: Susan Baker, Leslie Wilson, Terry Berkley

Continued on page 22

THURSDAY SESSIONS

Continued from page 21

LETTING GO: A Journey for Families and Self-Advocates
Topic Area: Community Living/ Advocacy
Speaker: Lynda Baumgardner

The Family As A Seminal Support to School and Community Inclusion: A 15 Year Journey
Topic Area: Community Living/ Family
Speaker: Daniel Dickman

Implementing Self-Management in the Workplace and Community
Topic Area: Community Living/ Housing
Speakers: Michal Post, Keith Storey

Building Working Relationships with Local One-Stops
Topic Area: Employment
Speaker: Norine Jaloway

Fighting for our Future - Resisting Peter Singer, Personhood, Futility and the "Duty to Die"
Topic Area: Euthanasia/Ethics
Speaker: Stephen Drake

Image 2002: We Are The Family
Topic Area: Family
Speakers: Pearl Wollin, Joan Carter, Lisa Anderson

Governmental Affairs Crackerbarrel
Topic Area: Governmental Affairs
Speakers: Bonnie H. Shoultz

The Impact of Inclusive Community-Based Instruction on Students with Varied Abilities in a High School
Topic Area: High School Inclusion / Inclusive Education
Speaker: Michele Flasch Ziegler

Planning for Successful Transitions from Elementary to Middle School
Topic Area: Inclusive Education/ Middle School Inclusion
Speakers: Mary Kathryn Wahl, Patricia K. McDaid, Lisa Pompei

Provision of Educational Support to Students with Disabilities in Two-year Postsecondary Settings
Topic Area: Inclusive Education; College/Transition
Speakers: Tom Harding, Teresa Whelley

Uniqueness of Asian Cultures and Linguistic Diversities Awareness
Topic Area: Multicultural
Speaker: Yvone Link

Tearing Down the Barriers to Full Inclusion: Indicators of Full Inclusion
Topic Area: Removing the Barriers to Full Inclusion
Speaker: Cheryl M. Jorgensen

Giving Voice to Students with Disabilities who have Successfully Transitioned to College
Topic Area: Research / Inclusive Education
Speakers: Deborah Durham Webster, Pete Flexer

An Examination of the Social Inclusion of Individuals with Disabilities in Religious Settings
Topic Area: Spirituality
Speakers: Pamela Lamar-Dukes, Charles Dukes

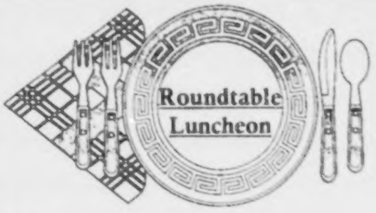
Parents' Impressions of Standards-Based Education for Student with Disabilities: Challenges, Rewards, and Suggestions for School Reform
Topic Area: Students who Challenge Schools But Do Not Have Labels of "Severe" Disabilities/Inclusive Education
Speakers: Stephanie Squires, Christine Templet

"Shame on You! You're Using the "R" Word, And He's Only 14 Years Old"
Topic Area: Transition / Family
Speaker: Richard Cozza

Helping Students Successfully Transition from School to the Community
Topic Area: Transition
Speakers: Victoria Dunlop, Paula Rush, Diane Kime, Irene Perry

Self-Advocacy and the Individualized Education Program (IEP)
Topic Area: Transition
Speakers: Carol R. Denson, Jacquelyn Gallagher, Diane Merrill

More than a Laughing Matter: Perspectives on Humor in Families Having Children with Disabilities
Topic Area: Urban Education
Speaker: Alicja Jarzab



Thursday, Nov. 15, 1:00 - 2:15 pm

Here are just a few of the interesting topics that will be featured at Thursday's Roundtable Luncheon:

- **Systems Change and Employment Outcome**
As a follow-up to the opening forum, join members of the Employment Committee to discuss trends and issues in systems change, with a goal of defining strategies for promoting expansion of employment opportunities at the state and local levels.
- **Postsecondary Choices and Challenges**
Join Caren Sax and others for an informal discussion over lunch to "chew on" the topics presented in the full-day focus area on access to postsecondary education.

TASH's work is dependent on the financial support of our members. We wish to acknowledge the generous assistance of our newest lifetime members

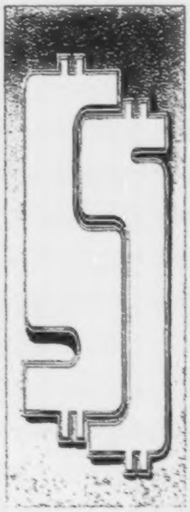
Kim Beloin ~ Grafton, Wisconsin
Sheila Romano ~ Naperville, Illinois
Robert Shepard ~ Castaic, California

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments. If you are interested in becoming a lifetime member of TASH, please contact Rose Holsey at 410-828-8274, ext. 100.

◆◆◆◆◆

Thanks, too, to the gracious donations of the following individuals:

Cynthia Azama
Center for Community Support
Linda Cole
Karen Davis
June Downing
Maxine L. Epperson
Beatrice B. Fink
Patty McCague
Lotte Moise
Anne Mitchell
Margaret Morone-Wilson
Susan Nadworny



Call for Conference Volunteers!

The TASH Annual Conference is already a great value. But if you want to stretch your conference dollars even farther, share some of the work with us, and we'll help with some of your expense!

We make it even easier for you to attend the TASH Conference! Just volunteer 10 hours and you'll receive **FREE** conference registration (**a $79-$369 value** depending on your registration category).

When you think TASH conference volunteer, think interesting, stimulating and fun! That's because many of the conference volunteer assignments involve one-on-one interaction with other attendees, presenters and exhibitors. Whether you volunteer to engage our youngest conference attendees by assisting at child care, (Club TASH Child Care Volunteers), assist keynote speakers at the General Sessions (General Session Volunteer), or help attendees in getting registration packets and other handouts (Registration Volunteer), you will enjoy the time that you spend as a TASH conference volunteer.

We have volunteer tasks and times to fit almost any schedule. There are even pre-conference volunteer assignments available in case you arrive in Anaheim a little early.

Don't delay! Volunteer assignments are made on a first come, first served basis. Contact Priscilla Newton, Volunteer Coordinator, at 410-828-8274, ext. 102 or send an e-mail to pnewton@tash.org and request a volunteer registration application today.

2001 TASH CONFERENCE SESSIONS

Friday, November 16

8:00 am — 9:00 am

Eight Steps to Effective Implementation of Alternate Assessments
Topic Area: Alternate Assessment/ Positive Approaches
Speakers: Sandra Thompson, Rachel Quenemoen

Leveling the Playing Field with One-to-One Computing
Topic Area: Assistive Technology
Speaker: Jerry Crystal

The Invisible Victims: Crime and Violence Against People with Disabilities
Topic Area: Criminal Justice
Speaker: Daniel D. Sorensen

Early Childhood Crackerbarrel
Topic Area: Early Childhood /Family
Speakers: Elizabeth Erwin, Jamie Ruppmann

Students with Disabilities Speak Out: National Focus Group Discussions on Supports and Barriers in Lifelong Learning and Employment
Topic Area: Employment / College
Speaker: Teresa Whelley

Transition from School to Work for Students with Ongoing Support Needs
Topic Area: Employment
Speakers: Ellen Condon, Twinkle Morgan, Norciva Shumpert

Parents Empowering Parents
Topic Area: Family/Collaboration
Speakers: Kim Kruger, Brenda McInnis

Tools for Navigating the Emotional Journey: Creating a Parenting Vision
Topic Area: Family
Speaker: Lisa Lieberman

Voices of Friendship: Why is it Still an Elusive Dream?
Topic Area: Friendship
Speakers: Jeffrey L. Strully, Carol Tashie, Zachary Rossetti

Introduction: Alternatives to Guardianship
Topic Area: Guardianship Alternatives
Speaker: Dohn Hoyle

Standing on Your Own Legs: A Writing Portfolio as a Way to Facilitate Composing for Culturally and Linguistically Diverse Students
Topic Area: High School Inclusion
Speaker: Ewa Jarzab

Moving From Self-contained, Segregated Models to Inclusive Models
Topic Area: Inclusive Education/ Teacher Development
Speaker: Jennifer J. Coots

Collaborative School Practices
Topic Area: Inclusive Education
Speakers: Amy Kuhns Bartlinski, Ann Harden

Two Stories of Inclusion
Topic Area: Inclusive Education
Speakers: Dianne Prohn, Karena Cooper-Duffy, Kathy Blossfield

"What the heck is SCRUNCH day?": The Creation of an Inclusive Middle School
Topic Area: Inclusive Education/ Middle School Inclusion
Speakers: Patricia K. McDaid, Lisa Pompei, Mary Kathryn Wahl

Key Elements of Building an Inclusive School: Connecting Students with Disabilities to whole School Reform
Topic Area: Inclusive Education/ Urban Education
Speakers: J. Michael Peterson, Lynne Tamor

Perceptions of Inclusive Education Held by General Education Teachers in Hong Kong, Taiwan, and US
Topic Area: Multicultural/International Issues
Speaker: Ming-Gon John Lian

Using Collaborative Partnership Research as a Tool for Training School
Topic Area: Personnel Preparation/ Inclusive Education
Speakers: Louis Gurecka, Pamela Gent, Richeal Anderson, Judy Heasely

In Their Shoes: Teachers Learning from Students with Disabilities
Topic Area: Personnel Preparation
Speaker: Robin Smith

Quality of Life through Opportunity Development
Topic Area: Positive Approaches
Speaker: Christopher teKampe

BIGGER IS BETTER: How to Assist Someone to Create a Bigger Life for Themselves and Decrease Behavioral Excesses in the Bargain
Topic Area: Positive Behavior Support
Speakers: Karre Williams, Kimberley Smalley

Related Services in the General Education Classroom
Topic Area: Related Services
Speaker: Michael McSheehan

School-wide Positive Behavior Support: Systems to Support the Inclusion of All Students
Topic: School -Wide Positive Behavioral Supports
Speaker: Rob Horner

A Giant Agency Transfers Control: A Four Year Update on Implementing Systems Change Using the Principles of Self-Determination
Topic Area: Self-Determination/ Systems Change
Speaker: James L. Dehem

Continued on page 25

FRIDAY SESSIONS

Continued from page 24

Imagine the Future: Would You Want to be an Adolescent with a Disability in an American High School Today?
Topic Area: Transition
Speaker: Frank R. Rusch

Friday, November 16

8:00 am — 10:15 am

Principles for Individual and Family Self-Determination Partnerships
Topic Area: Self Determination
Speakers: Laurie Powers, Ann Turnbull

Project ACTION Shares Successful Advocacy and Partnership Strategies
Topic Area: Advocacy
Speakers: Rebecca S. Salon, Phyllis Holton, Alvin Johnson, Robert Kennedy, Germaine Payne, Ricardo Thornton

Understanding Autism in New Ways
Topic Area: Autism
Speakers: Anne Donnellan, Martha Leary

Living a Valued Life
Topic Area: Community Living
Speakers: Laura Broderick, Jeffrey L. Strully, Dorothy Farrell

Writing and Implementing Social Stories: I'm in Trouble Again and I Don't Know Why!
Topic Area: Positive Approaches/ Inclusive Education
Speaker: Susan Deluke

Friday, November 16

9:15 am — 10:15 am

Taking Leadership in School Reform: Examining and Including Key Steps Toward Achieving the Goals of Self-Determination for America's Students
Topic Area: Advocacy
Speaker: Thomas Holub

Teaching Prerequisite Matching & Object Permanence Skills to Those Who Have Difficulty Communication with Pictures
Topic Area: Communication
Speaker: Marilyn Chassman

Facilitating Complete and Accurate Reports of Abuse in Children with Disabilities
Topic Area: Criminal Justice
Speakers: Rebecca Nathanson, Joe Crank

Teaching for Liberation: Lessons from Inclusive Schooling and Critical Pedagogy
Topic Area: Critical Pedagogy
Speakers: Paula M. Kluth, Rosario Diaz-Greenburg, Jacqueline Thousand, Ann Nevin

The Overwhelming Power of Visual Strategies for Improving Communication
Topic Area: Early Childhood/Speech Specialists
Speaker: Joan Green

Marketing Supported Employment Services
Topic Area: Employment/
Speakers: Cammie Cloman, Deb Skovron

Time for Us: Maintaining Your Adult Relationship When a Child has Challenges
Topic Area: Family
Speaker: Lisa Lieberman

Voices of Friendship: Essential Element
Topic Area: Friendship
Speakers: Zachary Rossetti, Carol Tashie

Crackerbarrel: Alternatives to Guardianship
Topic Area: Guardianship Alternatives
Speaker: Mayer Shevin

Including Children with High and Low Support needs in Upper Elementary Classrooms: The View from General and Special Educators
Topic Area: Inclusion Works/Inclusive Education
Speakers: Martha Snell, Christine A. Macfarlane

Creating New Possibilities: Family-School Partnerships
Topic Area: Inclusion Works
Speaker: Barbara Buswell

COLLEGE? Age Appropriate Options for 18-21 Year Students with Severe Disabilities
Topic Area: Inclusive Education/ Employment
Speakers: Lynn Quinn, JoAnn Genthner, Christine Lembach, Loisa Bennetto, Sherry Stulpin

Charlotte Alternate Assessment Model
Topic Area: Inclusive Education/ Alternate Assessment
Speakers: Diane Browder, Kathy Fallin, Stephanie Davis, Susan Griffin

Schools in Italy: Tomorrow, Today
Topic Area: Multicultural/Inclusive Education
Speaker: Carol Berrigan

Sharpening the Saw: Maintaining Cutting Edge Professional Skills in the Field
Topic Area: Personnel Preparation/ Professional Develop
Speakers: Donna R. Wickham, Megan S. Cote, Gwen Beegle, Susan Bashinski, Joan Houghton, Wendy Blaauw, Rachel Freeman

Postmodernism and Special Education: Valuing Faculty Diversity in Higher Education
Topic Area: Personnel Preparation
Speakers: Valerie Owen, Patrick Schwarz, Pennie Olson, Paula K. Neville, Terry Smith

Continued on page 27

KiDDiE CORP

We'll handle the kid stuff.

KiddieCorp National Headquarters
10455 Sorrento Valley Road
Suite 200
San Diego, CA 92121
Tel: 800-942-9947
Fax: 858-455-5841

TASH Conference Club TASH

Thank you very much for your interest in the TASH children's program. Our goal is to provide your children with a program that they want to attend, while providing you with that critical "peace of mind" feeling so that you can attend event activities.

KiddieCorp is pleased to provide a children's program for TASH. KiddieCorp is in its fifteenth year of providing high quality children's programs and youth services to conventions, trade shows and special events. We take watching your children very seriously. KiddieCorp has enjoyed long-time partnerships with TASH, which has helped to establish KiddieCorp as a premier provider of event children's program services.

ACTIVITIES

All activity planning is based around the program hours and ages of the children. Activities include exciting themes, arts & crafts, group games, music & movement, board games, story time, dramatic play, etc. We provide activities appropriate for each age group, using safe, sturdy equipment that you can feel comfortable with. Children can make their own choices within KiddieCorp's program.

COMMITMENT

Our goal is to provide your children with a comfortable, safe and happy experience. Our staff to child ratios are high to ensure that every child feels special (1:2 infants; 1:3 toddlers; 1:5 school age). KiddieCorp team members are selected according to their integrity, experience, education and enthusiasm. They must be wonderful with kids! You will feel extra secure knowing that the KiddieCorp team is bonded and that we carry ample liability insurance.

## WHERE, WHEN, FOR WHOM

The program is for children ages 6 months to 12 years of age. The dates for the program are November 14-17, 2001 and will be located at the Anaheim Marriott in Anaheim, California. Snacks and beverages will be provided and meals need to be supplied by parents or purchased when checking your child in each day. The nominal cost for this service is $2.00 per hour plus a $5.00 per child sign-up fee.

REGISTRATION

For a registration/consent form, please call 1-800-482-8274 or email dmarsh@tash.org. Space is limited, so registrations are only guaranteed if received by the pre-registration deadline (October 14, 2001). TASH/KiddieCorp must receive both the registration/consent form, child profile form, and payment in full to hold reservations. Although every effort will be made to accommodate late or on-site registrations, there is no guarantee that KiddieCorp can accept children unless they are pre-registered.

NEED MORE INFORMATION?

KiddieCorp is always available by phone, fax, and e-mail to answer any of your questions. Feel free to contact KiddieCorp's program manager by phone at 858-433-1718, by fax at 858-455-5841 or by e-mail at tashkids@kiddiecorp.com

Friday Sessions

Continued from page 25

What Have We Learned About Successful Inclusion and Authentic Curriculum From 8 Wisconsin Schools
Topic Area: Positive Approaches
Speakers: Kim S. Beloin, Paula Dehart, JoEllen Anderson

Communication and Literacy Supports: The New Possibilities of Inclusion
Topic Area: Related Services
Speaker: Michael McSheehan

The Influence of Gender on Friendship Expectations of Students in Middle Schools Toward Peers with Severe Disabilities
Topic Area: Research
Speakers: Janis Chadsey, Kyoung Gun Han

Urban Schools and Positive Behavior Support: Implications of Inclusive Systems
Topic Area: School-Wide Positive Behavioral Supports
Speaker: Wayne Sailor

Community, Citizenship and Self-Determination
Topic Area: Self-Determination
Speaker: Marilyn Kuna

Social Supports for the Development and Maintenance of Sexuality Knowledge and Expression
Topic Area: Sexuality/Sexual Expression
Speaker: Charles Dukes

Teaching Students to Support Themselves in Inclusive Education
Topic Area: Social Justice / Inclusive Education
Speakers: Martin Agran, Carolyn Hughes, Susan Copeland, Michael Wehmeyer

The Inclusive Charter School (CHIME) at California State University, Northridge
Topic Area: Teacher Development
Speakers: Claire Cavallaro, June Downing, Julie Fabrocini, Delia Smith, Patrick Smith

Friday, November 16

12:15 pm — 1:15 pm

Changing Times
Topic Area: Advocacy/Positive Approaches
Speakers: Cheryl Monk, Jerry Wooliver, Sherry Lookabill, Megan Seelye

Forensic Advocacy Services
Topic Area: Advocacy/Criminal Justice
Speakers: Kevin Farrar, Rebecca Treiber

New Strategies and Methods of Supporting People with Autism
Topic Area: Autism
Speaker: Sally Young

The Images of Television
Topic Area: Communication
Speaker: Gayle Gardner

Promoting Awareness, Communication, and Safety (PACS): A Partnership Between the Disability and Law Enforcement Communities
Topic Area: Criminal Justice/ Communication
Speakers: Jeffery Schwamm, Phyllis Holton, Donti Mcfield

Social Inclusion in the Supported Employment Workplace
Topic Area: Employment/Transition
Speakers: Jeanne Novak, Patricia Rogan

The Power of Creativity and Family in Shaping the Future
Topic Area: Family/Health
Speakers: Diane Hovey, Jessica Hovey

Time Extensions as Reasonable Accommodation in a State Rules Promulgation Process - A Case Study
Topic Area: Family
Speakers: Ann Turnbull, Calvin Luker, Tricia Luker

Moving Toward Supports in Decision-making as an Alternative to Guardianship
Topic Area: Guardianship Alternative/ Self-Determination
Speakers: Duncan McNelly, Mary Sykes, Maya Fairchild

Usefulness of a Portfolio Process for Educators in Inclusive Settings
Topic Area: Inclusive Education/ Alternate Assessment
Speaker: Ellin Siegel

Academic Inclusive Momentum Project
Topic Area: Inclusive Education
Speakers: Marlene Johnson, Mary Lasater

Organizing an Inclusive Classroom: A Triangle of Supports
Topic Area: Inclusive Education
Speaker: Nancy Frey

Getting Together and Organized
Topic Area: Multicultural
Speaker: John Sanford

The Real Thing: Using a Case-Study Approach in College Classrooms
Topic Area: Personnel Preparation
Speaker: Cynthia F. Sutton

Reclaiming the Power of the Heart, Teaching and Inspiring Values for All. Can the Concept of Quality of Life Make a Difference in the Lives of Persons with Disabilities?
Topic Area: Positive Approaches / Quality of Life
Speaker: Anthony McCrovitz

Communities Unlimited: Using the Keys to Open the Doors
Topic Area: Positive Approaches/ Community Development
Speakers: Cheri Novak, Paula Bohland, Gary Robinson

Continued on page 28

FRIDAY SESSIONS

Continued from page 27

Welcome to Our World of Choice
Topic Area: Positive Approaches
Speakers: Elizabeth Fussell, Tracy Berrong, Steve Jacobs, Mary Ann Schenk, Treva Maitland, Mary Dell Green, Pam Brandon, Lisa Manus

Behaviorist Heal Thy Self
Topic Area: Positive Behavioral Support
Speakers: Kimberley Smalley, Karre Williams

Measuring the Quality of Services: Making Sure Your Priorities are Met
Topic Area: Research
Speakers: Sara Karon, Kristen Voskuil

The Ask Me Project: Consumers Involved in Quality of Life
Topic Area: Self Determination
Speakers: Sarah Basehart, Tracy Wright, Gordon Bonham, Joan Rumenap, Linda Essenmacher

If I Can't Control My Money, It Ain't Self-Determination
Topic Area: Self-Determination
Speakers: Gerald J. Nebeker, Marilyn Bown

Lessons of Thoughtful Action
Topic Area: Teacher Development
Speakers: Candee Basford, Pam Young, Tag Fox, Tia Stryker

Planning for the Future with a Little Help from My Friends
Topic Area: Transition/Self-Determination
Speakers: Barbara Purvis, Colleen Thoma

The Nuts and Bolts of Systemic Change for Inclusive Practices in Urban Schools
Topic Area: Urban Education
Speakers: Christine Salisbury, Ann T. Halvorsen

Friday, November 16

12:15 pm — 2:30 pm

Freedom of Speech over the Internet: Making it Accessible to All
Topic Area: Advocacy
Speaker: Don O'Callahan

Planning for the Diverse Classroom
Topic Area: Inclusive Educaton
Speakers: Linda Davern, Roberta F. Schnorr

Voices of Friendship: Barriers to Friendship
Topic Area: Friendship
Speakers: Carol Tashie, Zachary Rossetti

Friday, November 16

1:30 pm — 2:30 pm

Self Advocates March On the State House: Advocating for Change with Legislators
Topic Area: Advocacy/Governmental Affairs
Speakers: Carol Warner, Kim Daniels, Sue Ciappara, Phil Smith

Involved Effective Parents in the IEP Process
Topic Area: Advocacy
Speaker: Alison Seyler

How to be a True Survivor - Tips and Ideas for Remaining Safe In Today's Busy and Sometimes Not So Safe World
Topic Area: Advocacy/Self-Determination
Speaker: Trish Baker

Pennsylvania's Performance Based Model of Alternate Assessment
Topic Area: Alternate Assessment
Speakers: Donna Lehr, Naomi Zigmond, Jill Greene

Assessing Children's Assistive Technology Needs through Video Conferencing
Topic Area: Assistive Technology
Speakers: Thomas J. Simmons, Debra Bauder, Preston Lewis

My Life - My Words
Topic Area: Autism
Speaker: Mayer Shevin

Cooperative Learning: Learning and Playing Together in Inclusive Classrooms
Topic Area: Curriculum
Speaker: Mara Sapon-Shevin

Building Community Connections: A Networking Approach for Transition Age Students
Topic Area: Employment
Speaker: Colleen O'Mara

The Grassroots Consortium on Disabilities - Providing Community - Based Services for Culturally Diverse Families
Topic Area: Family
Speakers: Theresa Cooper, Luyen Chu, Alice Harris

Person Centered Planning as an Alternative to Guardianship
Topic Area: Guardianship Alternatives
Speaker: Sally Burton-Hoyle

Leadership for Inclusion and Public Purpose
Topic Area: Inclusive Education/Leadership
Speaker: Diane Ketelle

Practical Strategies to Assist in the Inclusion of Children with Autism in Elementary School
Topic Area: Inclusive Education/Autism
Speakers: Judy Terpstra, Donna Del Rio-D'Elia

Creating Inclusive Learning Environments Using Multiple Intelligences
Topic Area: Inclusive Education
Speakers: Katie Johnson, Mary Falvey

Continued on page 29

FRIDAY SESSIONS

Continued from page 28

Building Inclusive Schools: We Are All the Thread and the Needle
Topic Area: Inclusive Education/ Urban Education
Speakers: Janice Colliton, Bonnie James, Sandy Widmer, Barbara Mick, Tricia Coger, Brenda Vaughn, Carlos Lopez, Sasha Roberts-Levi, Lynne Tamor, Michael Peterson, Rich Gibson

At the Table: The Multicultural Disabilities Network Washington State 2001
Topic Area: Multicultural
Speakers: Susie Schaefer, Ginger Kwan, Regina Harris, Loxic Balthazen, Jenny App, Steve Elliott

The Effects of Combining a Teacher Support Program with a Master of Arts and Education Degree Program in Severe Disabilities on Graduate Students at Western Carolina University
Topic Area: Personnel Preparation
Speakers: David L. Westling, Karena Cooper-Duffy, Kenneth Prohn

Eye Listen - Do You?
Topic Area: Positive Approaches
Speakers: Mark Vincent, Scott Ryder

Communication and Literacy: Roles of Related Service Providers and Educators
Topic Area: Related Services
Speaker: Michael McSheehan

Quality? Bah! Where is the "Consumer Reports" Paradigm in Our Field?
Topic Area: Research/Quality of Life Choices
Speakers: Ami Sullivan, James W. Conroy, Sherry Beamer

Building a Positive Social Culture in Schools
Topic Area: School-wide Positive Behavior Supports
Speakers: Lisa Cushing, Rob Horner

Spirituality & Sexuality: How the Two Can Be Connected
Topic Area: Sexuality
Speaker: Kathryn O'Connell

Quit Passing the Buck
Topic Area: Transition/Employment
Speakers: Rita Skiles, Jerry Gronewold

Friday, November 16

1:30 pm — 3:45 pm

Strategies for Providing Inclusion Support for Young Children with Intensive/Specific Needs
Topic Area: Early Intervention
Speakers: Diane Klein, Anne Marie Richardson-Gibbs, Brigitte Ammons

CLEAR Progress in Inclusive Schools: Developing and Working with an Inclusive Schools Leadership Network
Topic Area: Teacher Development/ Inclusive Education
Speakers: Ann T. Halvorsen, Linda Lee, Heidi Bjorgan, Kristen Lombardo, Sandra Osborne

Friday, November 16

2:45 pm — 3:45 pm

QualityMall.org: Person-Centered Services Supporting People with Developmental Disabilities
Topic Area: Communication/
Speakers: John G. Smith, Jerry Smith, Angela Novak Amado

The National Alliance for Direct Support Professionals: Grass Roots Efforts to Build a Stronger Workforce
Topic Area: Community Living
Speakers: Carole L. Thibodeau, Marianne Taylor, Cliff Poetz

Crackerbarrel on Critical Pedagogy
Topic Area: Critical Pedagogy
Speaker: Donald Cardinal

Transcending Traditional Services: Strategies in Planning a Large Scale Conversion
Topic Area: Employment
Speakers: Ervin J. Picha, Cecelia Coverdale

Positive Alternatives for Families Facing Disability Challenges: Empowering Parents in an Urban Community
Topic Area: Family/Community Involvemen
Speakers: Michaela Farber, Ravita Maharaj, Jeffery Schwamm

Voices of Friendship: Further Questions to Ponder
Topic Area: Friendship
Speaker: Jeffrey L. Strully

The Power of Trusts as an Alternative to Guardianship
Topic Area: Guardianship Alternatives
Speaker: Dohn Hoyle

Who Ya Gonna Call? State Technical Assistance Networks
Topic Area: Inclusion Works
Speakers: Cheryl Liles, Carol Quirk

Adapting Curriculum: Person #58 is Paul Revere
Topic Area: Inclusive Education/ Middle School Inclus
Speakers: Lisa Pompei, Patricia K. McDaid, Mary Kathryn Wahl

Putting the Pieces Together: Statewide Implementation of a Portfolio-Based Alternate Assessment System
Topic Area: Inclusive Education / Assessment
Speakers: Shaunna Crossen, Brian Touchette, Janine Weber, Kellie Anderson, Donald L. Peters

Continued on page 31

The World Congress & Exposition on Disabilities
Sept. 28-30, 2001

Now in its second year, the World Congress & Exposition on Disabilities (WCD) presents a comprehensive forum to educate, inform, and provide a useful exchange of ideas for persons with disabilities and special healthcare needs, as well as for family members, caregivers and those who work in the disabilities field. The event, scheduled for September 28 - 30 at the Georgia International Convention Center in Atlanta, is organized by H.A. Bruno, LLC.

The conference portion of the show, comprised of over 65 seminars, is produced by the EP Foundation for Education, Inc., a 501(C)3 not-for-profit organization. CME and CEU accreditation is available for many disciplines. Sessions on adapted physical education are sponsored by PALAESTRA magazine and the American Association for Active Lifestyles & Fitness (AAALF). Attendees will also have an opportunity to examine the latest products and services from more than 250 exhibitors representing pharmaceutical, computer, automotive, mobility, personal care, insurance, nutrition, and travel industries.

Special features will again include a career fair, a sports and recreation activity center sponsored by McDonald's Corp. and U.S. Disabled Athletes Fund, and an assistive technology learning center. For more information on WCD, visit www.wcdexpo.com or call 877-WCD-EXPO

We're looking
for you!

Attention TASH Members!

The Paraeducator Interest Group is seeking contact information from members who are interested in issues related to the employment, deployment, training and support needs of paraeducators.

If you are interested in issues related to paraeducators, please send an e-mail to Nancy Weiss at the TASH central office <nweiss@tash.org> expressing your desire to be a member of the Paraeducator Interest Group. We will send respondents a copy of the TASH Resolution on Paraeducators, build a resource network and communicate relevant information to you.

Friday Sessions

Continued from page 29

Implications for Change: How to Motivate Educators to Continue Teaching in Inclusive Classrooms
Topic Area: Inclusive Education/High School
Speakers: Veronica Moore, Liz B. Keefe, Eddie del Rosario

Inclusive Classrooms as Inclusive Communities
Topic Area: Inclusive Education/ Urban Education
Speakers: Lynne Tamor, Michael Peterson, Sandy Widmer, Sasha Roberts-Levi, Mishael Hittie, Sue Huellmantel, Tanya Sharon

Snakes and Ladders: An Exploration of the Intersection of Cultural Perceptions of Disabilities, the Culture of Schools (Special Education), and South Asian Americans
Topic Area: Multicultural/Family
Speaker: Zara Dee Mehta

Planning and Evaluating Classroom Supports
Topic Area: Related Services
Speaker: Michael McSheehan

Designing Function-Based Support in Schools
Topic Area: School-wide Positive Behavioral Supports
Speaker: Richard Albin

Demanding Our Rights: The Fight by Maine Self-Adocates to Keep the Vote
Topic Area: Self-Advocacy/ Governmental Affairs
Speakers: James Oldenburg, Steve Porter

Self Determination Activities in New Jersey
Topic Area: Self-Determination
Speaker: Sue Henshaw

Quality of Life: Are We Making A Difference?
Topic Area: Transition
Speakers: Adelle Renzaglia, Margaret Hutchins

Friday, November 16

2:45 pm — 5:00 pm

Multiple Intelligences in Inclusive Classrooms: Teaching Strengths and Standards
Topic Area: Inclusive Education
Speaker: Robin Smith

Person-Centered Tools for Change: The CD-Rom
Topic Area: Community Living
Speaker: Jack Pearpoint

Media Advocacy: Getting Our Issues into the Mainstream
Topic Area: Media
Speakers: Jennifer Burnett, Janine Bertram-Kemp

Preparing for Noah: How I Used a Circle of Support to Prepare For The Birth of My Son
Topic Area: Advocacy
Speakers: Santa Perez, Colleen Thoma, Barbara Purvis

If the Cure Isn't Found, Let's Look Into the Future
Topic Area: Autism
Speakers: Martha Leary Jeffrey L. Strully, Anne Donnellan, Mayer Shevin

Family Support-What's Old, What's New
Topic Area: Family
Speakers: Fran Smith, Susan Yuan

Building Linkages between Assessment and Instruction: Outcomes-Oriented Curricula Design for Students with Multiple Disabilities
Topic Area: Inclusion Works
Speaker: Jan Writer

Status of Chanda Smith vs. Los Angeles Unified School District Consent Decree Process
Topic Area: Inclusive Education/ Governmental Affairs
Speaker: Barbara Marbach

Project for Supported Living - STRIVE Program
Topic Area: Leisure and Recreation
Speakers: Peter Brown, Lori Rogers, Kaley Young, Cecily Merill, Katie Brennan, Noel Thompson

LIVE Experiencing Interactive Courses in "Severe Disabilities over the Internet - THE SEQUEL!
Topic Area: Personnel Preparation
Speakers: Fred Spooner, Martin Agran, Richard Kiefer-O'Donnell

Self-Determination: An Interpretation by People with Disabilities
Topic Area: Self-Determination
Speakers: Edna Bonham, Keith Bonham

Friday, November 16

4:00 pm — 5:00 pm

Explaining What We Observe Builds Relationships That Lead to Better Medical or Psychiatric Care
Topic Area: Advocacy/Health Care
Speaker: Laurie Kimball

Acceptability of Language Interventions: Teachers' Perception
Topic Area: Communication
Speaker: Yasemin Turan

Reaching for the STARS
Topic Area: Community Living
Speakers: Julie Silver, Marianne Taylor, Minona Heaviland

Successes and Challenges of Early Inclusion
Topic Area: Early Intervention
Speakers: Diane Klein, Brigitte Ammons, Anne Marie Richardson-Gibbs

Continued on page 32

TASH: Public Policy In Action

Rally for A Real Life In the Community!

You are invited to celebrate with us as we reaffirm our commitment to a real life for every citizen with disabilities and to equitable wages and benefits for every person who provides assistance, coaching, support and services in the community!!

- Celebrants will be joined by Cal TASH, Tom Gilhool, Max Lapertosa, Barbara Ransom and Judy Gran of PILCOP as we rally on behalf of the groundbreaking *Sanchez* case filed in California. This case seeks to ensure that people who work in community settings are paid as much as people working in institutions and nursing homes.

Meet and greet the families and self-advocates who have brought about the *Sanchez* action and add your voice to theirs in solidarity for the cause of community! Co-sponsored by Cal-TASH, DREDF, and PILCOP.

FRIDAY, NOVEMBER 16, 2001
Activities will begin at 12:00 noon in the Ballroom of the Marriott!

FRIDAY SESSIONS

Continued from page 31

How Far Have We Come? What More Can We Do? A 15-year Analysis of Employment Outcomes for Individuals with Multiple Disabilities
Topic Area: Employment
Speakers: Rachel Koosed, Linda Seppala

Family Interventions for Children with Autism
Topic Area: Family
Speakers: Jennifer Symon, Yvonne Bruinsma, Rosy Fredeen, Lauren Brookman, Robert Koegel, Lynn Kern Koegel

Living Their Own Lives: Self Determination vs. Guardianship
Topic Area: Guardianship Alternatives
Speaker: Dohn Hoyle

Partner Learning: The Power Source for Students, Schools and Communities
Topic Area: Inclusive Education/Early Childhood
Speakers: Antonette Hood, Mary E. McNeil

The Demography of Inclusive Education
Topic Area: Inclusive Education
Speakers: Noel Kulik, Barbara W. Leroy

Communication, and Literacy: The Future of Related Services and Inclusive Schools
Topic Area: Related Services
Speakers: Donald Cardinal, Cheryl M. Jorgensen

The Complexities of Inclusive Schooling: Student Voices
Topic Area: Research
Speakers: Laurie R. Lehman, Valerie A. Lava

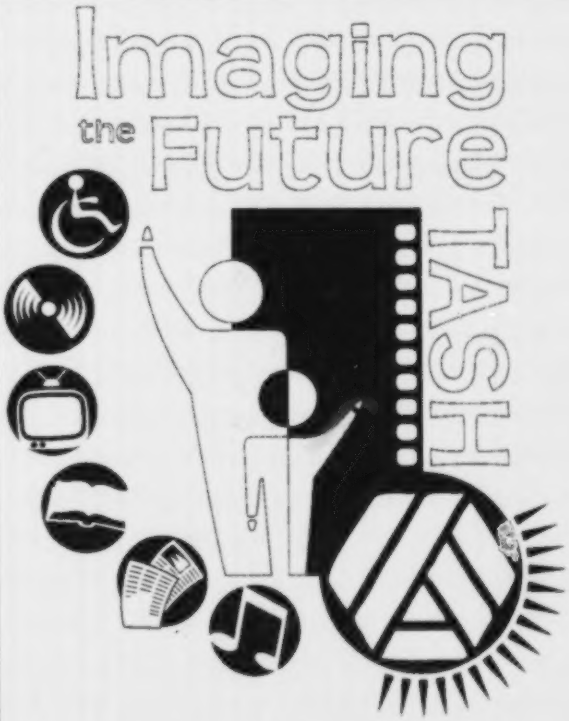
Future Directions for School-wide Positive Behavior Support
Topic Area: School-wide Positive Behavior Support
Speaker: Tim Knoster

A Consumer Perspective on Self-Determination
Topic Area: Self-Determination
Speakers: Chester Finn, Bonnie H. Shoultz

One Accountability System for All Students: Maine's Alternate Assessment
Topic Area: Statewide Alternate Assessment
Speakers: Maria Timberlake, Betsy Enright

Curricular Adaptation: Providing Quality School-Wide Training
Topic Area: Teacher Development
Speakers: Nanho S. Vander Hart, Dolores Gribouski

Transition Assessment: Strategies that Teachers and Students Use to Determine Student Preferences and Interests
Topic Area: Transition
Speakers: Colleen Thoma, Mary F. Held, Ron Tamura, Kimberly Isbell, Joel Mills



TASH Announces a Dynamic Call for Image Award Nominees!

This year at the Annual Conference to be held in Anaheim, November 14-17, 2001, TASH will confer a series of awards around the theme "*Imaging the Future.*" These awards will honor the groundbreaking and exemplary work of individuals and companies to create and promote positive images of people with disabilities. Image Award recipients will be honored at a Showcase of Images Reception on Thursday evening, November 15th.

To nominate an advertisement, commercial, television show, movie, publication, artist, or any medium you think has met the criteria listed here and has made significant impact on the positive images of people with disabilities, send full details regarding the nomination, including name(s) of the company or individual; complete contact information; and specific details about the medium for which the individual or company is being nominated.

TASH
29 W. Susquehanna Ave, Suite 210
Baltimore, MD 21204
Ph: 410-828-8274 ❖ Fax: 410-828-6706
www.tash.org

TASH Image Awards

Criteria *(work needs to meet one or more):*

- ◇ Emphasizes inclusion or civil rights aspects of issues or stories
- ◇ Supports self-determination and or independent living philosophy
- ◇ Promotes empowerment
- ◇ Values the civic participation of individuals with disabilities
- ◇ Contributes to the shaping of positive images and helps to eliminate stereotypes by accurately portraying people with disabilities
- ◇ People with disabilities are the primary source(s) of information
- ◇ Accessible (must be available in alternate format such as captioned, large print, etc.)
- ◇ Portrays Diversity

Nomination Categories

☐ Exemplary Achievement Awards
(Given to persons or companies that have made ongoing and significant contributions to public awareness and understanding of people with disabilities through the media)

Nominations in the following categories must have appeared between Jan. 2000 and Sept. 2001.

- ☐ Print (magazine, newspapers, newsletters)
- ☐ Disability Rights Media
- ☐ News (local, national, morning, magazine format)
- ☐ Public service announcements
- ☐ Entertainment
    - ○ Primetime drama
    - ○ Primetime comedy
    - ○ Children's programming
    - ○ Daytime drama
    - ○ TV movies/mini-series
    - ○ Specials
- ☐ Feature films
- ☐ Documentaries/Educational films
- ☐ Print Advertising
- ☐ Electronic Advertising
- ☐ Live theater
- ☐ Internet
- ☐ Radio
    - ○ Public Service Announcements
    - ○ News
    - ○ Public Affairs Programming

2001 TASH Image Award Application

- Applications due September 15, 2001 -

How to Apply:

(1) Complete this application form as fully as possible. Nominations may be submitted by anyone, and a product maybe nominated in more than one catetory.

(2) Attach a brief narrative discussing why the nomination is being made.

(3) To be considered, the original completed application and supporting materials must be received in the TASH central office no later than **September 15, 2001.**

❖ Films, commercials, or television shows should be submitted on a standard VHS tape.
❖ All other materials require a printed copy of ad or article from the publication.

* All submitted materials become the property of TASH for the sole use of the Positive Images Awards Committee.

Send to:

Awards Committee
TASH
29 West Susquehanna Avenue, Suite 210
Baltimore, MD 21204
Phone: 410-828-8274
Fax: 410-828-6706

Nominator

Name:______________________________
Street Address:________________________
City:______________________________
State/Province:__________ Country:__________
Zip/Postal Code:________________________
Daytime Telephone: (___)____________________
Evening Telephone: (___)____________________

Nomination Category:

- ☐ Exemplary Achievement Awards
- ☐ Print (magazine, newspapers, newsletters)
- ☐ Disability Rights Media
- ☐ News (local, national, morning, magazine format)
- ☐ Public service announcements
- ☐ Entertainment
  - ● Primetime drama
  - ● Primetime comedy
  - ● Children's programming
  - ● Daytime drama
  - ● TV movies/mini-series
  - ● Specials
- ☐ Feature films
- ☐ Documentaries/Educational films
- ☐ Print Advertising
- ☐ Electronic
- ☐ Live theater
- ☐ Internet
- ☐ Radio
  - ● Public Service Announcements
  - ● News
  - ● Public Affairs Programming

Name of Media Product Nominated______________________________
Produced By____
Where it appeared:____________________ **When it appeared:** ____________
Contact Name:________________ **Phone:**____________________
Address:____________________________ **Email:**______________
Reason Nominated:______________________________________

2001 TASH CONFERENCE SESSIONS

Saturday, November 17

7:30 am — 10:00 am

POSTER SESSIONS

Expressing Themselves: High Schools Students' Use of Voice Recognition Programs
Topic Area: Assistive Technology
Speakers: Delann Soenksen, Sandra Alper, Charlotte Mull

Inclusive Acts: An Integrated Playgroup Examined
Topic Area: Autism
Speaker: Marilyn Lauer

Addressing Behavior Challenges Through Self Management Strategies
Topic Area: Best Practice/Students who Severely Challenge Schools But Who Do Not Have Labels of "Severe" Disabilities
Speakers: Jessica Beasley, Melanie Hammond Christian

Toward Including in Competitive Team Sports
Topic Area: Competitive Team Sports/ Leisure/Recreation
Speaker: Yoshihisa Ohtake

A Follow-up Evaluation of Staff Development in an Inclusive Childcare
Topic Area: Early Childhood
Speaker: Kwang-Sun C. Blair

Effects of Activity-based Integrated Preschool Curriculum (AIPC) for Korean Young Children with Disabilities
Topic Area: Early Childhood/ Multicultural
Speakers: Eunhye Park, Sohyun Lee

Involving Supported Employees in the Development of a Job Satisfaction Survey
Topic Area: Employment
Speakers: Lori Garcia, Lewis Persons

A Systems Approach to Placement
Topic Area: Employment
Speakers: Madan Kundu, Alo Dutta

An Assessment Tool for Measuring the Characteristics and Culture of Job Sites
Topic Area: Employment / Research
Speaker: Hyun-Sook Park

The Standard Rules of the United Nations of the Equalization of Opportunities for Persons with Disabilities
Topic Area: Ethics/Rights/ Multicultural
Speakers: Maria Del Carmen Malbran, Claudia Villar

The Optimal Praise: Praise That Does Not Demean nor Extol
Topic Area: Family
Speaker: Alicja Jarzab

The Children's Link Society
Topic Area: Family/Collaboration
Speakers: Brenda McInnis, Kim Kruger

Family Support of the Health Care Needs of People with Disabilities: Two Practical Tools
Topic Area: Health Care/Family Support
Speakers: Dina McFalls, Carol Persons

Supporting High School Students to Engage in Recreational Activities with Peers
Topic Area: High School Inclusion
Speakers: Susan Copeland, Stephanie Fowler, Carolyn Hughes, Penny Church-Pupke

The Inclusive Education Instructional Project
Topic Area: Inclusive Education
Speakers: Vicki A. McGinley, George Drake

Quality of life for Students with Severe Disabilities Who Attend Their Neighborhood Schools
Topic Area: Inclusive Education/Best Practices
Speaker: Jill Greene

Person Centered Transition Planning and the Self-Directed IEP
Topic Area: Transition
Speakers: Paul Bates, Craig Minor

Facilitating Social Interactions: A New Design for Early Childhood
Topic Area: Inclusive Education / Early Childhood
Speakers: Catherine Lyons, Keith Hyatt

Positive Peer Pressure: Using Peers to Assist Students with Disabilities
Topic Area: Inclusive Education
Speaker: Carolyn Auld

Current Practices in Inclusive Education
Topic Area: Inclusive Education/All Grade Levels
Speakers: Amy Hanreddy, Shawna Olson, Sheri Widman, Anna Colilles Fuentes, Ann Dillenback, Igor Veremeykin

We Feel Included Here: A Unique Collaboration to Serve Preschool Children in their Neighborhood Preschool
Topic Area: Early Childhood
Speaker: Amanda Ferlon

Electronic Resource Guide
Topic Area: International Inclusion/ Online Resource Guide
Speakers: Ronda Sortino, Karen Minor, Beth Mann, Sandy Moore

Hey, Why Weren't You at the Gym!!
Topic Area: Leisure and Recreation
Speakers: Michael Shanzer, Beth Shanzer

Continued on page 36

SATURDAY SESSIONS

Continued from page 35

Strategies for Incorporating New State and Federal Mandates into Training Program for Teachers for Students with Severe Disabilities
Topic Area: Personnel Preparation
Speakers: Michael Hannum

Organized Chaos: A Collaborative Model of Distance Delivery Training
Topic Area: Personnel Preparation
Speakers: Mary Cavalier, Roxann Lamar

Infusion: Modeling Special Education within a New Teacher
Topic Area: Personnel Preparation
Speaker: Christine A. Macfarlane

Project GOAL: Guaranteeing Opportunities for ALL Learners (including those with Low-Incidence Disabilities)
Topic Area: Personnel Preparation
Speakers: Sandra Hopfengarder Warren, Melissa Engleman

Imaging Our Values: Pre-Service Teachers' Creative Images
Topic Area: Personnel Preparation/ Research
Speakers: Randy Seevers, Sylvia Martin, Debra Baker

Issues in Developmental Disabilities: An Interdisciplinary Survey Course on Developmental Disabilities
Topic Area: Personnel Preparation
Speaker: Charles Degeneffe

The Hundredth Monkey: A Prophet of Inclusion
Topic Area: Positive Approaches
Speaker: Janet Fehr

The Prespectives of Individuals with Disabilities and Challenges Behavior on Challenging Behavior
Topic Area: Research
Speaker: Mike Ruef

The Definition, Meaning, and Process of Community from the Perspective of Six Individuals with Significant Disabilities
Topic Area: Research
Speaker: Joanna Royce-Davis

Putting the Social Model into Practice
Topic Area: Research
Speaker: Susan Neely-Barnes

From School to the Real World: A Portrait of Family Transition
Topic Area: Research/Transition
Speakers: Debra Baker, Sylvia Martin

Overview of the Special Education Elementary Longitudinal Study (SEELS): A National Study of Special Education
Topic Area: Research
Speakers: Susan U. Marks, Jose Blackorby, Jennifer Shaw-Hegwer

Lifestyles Management: An Education & Support Group for Individuals Seeking Healthy Change
Topic Area: Self-Determination/ Health
Speakers: Susan Wilson, Kaydee Sullivan

Realizing Dreams - The Journey So Far
Topic Area: Self-Determination/
Speakers: Sandra Mak, Linda Pollitt, Craig DeCoux, Shawna Churchill, Clarence Hastings

Imaging the Future: Student Stories in Words and Pictures
Topic Area: Transition
Speakers: Karen Zimbrich, Debra Hart

Saturday, November 17

10:00 am — 11:00 am

Muticultural Families and the Transition to Adulthood: Issues and Strategies for Success
Topic Area: Family
Speaker: Mary Morningstar

Issues Surrounding Teacher In-service Training - "It's Like Herding Cats"
Topic Area: Personnel Preparation
Speakers: Christy Gunn, Mariel Zeller, Michael Burdge

IDEA 97-VR Act & the IEP Transition Team
Topic Area: Transition
Speakers: Luz Elena Aponte, Milton Aponte, Berthy De La Rosa-Aponte, Al Farias, Sandra Obando

Navigating the Maze of Transition
Topic Area: Transition
Speakers: Melissa A. Brown, Pam Vesley, Jayne M. Stooksbury

Saturday, November 17

10:00 am — 12:15 pm

Win Social Security's Money
Topic Area: Employment/Advocacy
Speaker: Tyler Paris

Getting to the Dream
Topic Area: Employment
Speaker: Denise Sosbe

Involved Effective Parents in the IEP Process
Topic Area: Family
Speaker: Ginette Goldfeld

Dancing as a Team
Topic Area: Management Issues/ Employment
Speakers: Debra Whitehead, Tyler Paris

Evansville ARC
seeks an Executive Director/CEO

Job Description: Evansville ARC has a top leadership opportunity as an Executive Director/CEO. Demonstrated leadership skills are a must. This leader will be responsible for executive management as well as directing, administering, and coordinating agency activities in support of policies, goals, and objectives established by the Board of Directors.

A master's degree in human services, public or business administration or a related field with a minimum of 7 years of management preferably in an ARC or rehabilitation organization is required. Experience working with board of directors, financial and personnel issues, outcome systems, and program services development is a must. This leader should display a superb and highly polished communication style in all settings with excellent interpersonal skills and have the highest standards of integrity and commitment.

Organizational Background: Evansville ARC, Inc., is a private, not-for-profit CARF accredited agency with an $8 million dollar budget and 160+ employees serving over 600 persons with developmental disabilities. For almost 50 years, Evansville ARC has been providing Early Childhood Services, Adult Habilitation and Supported Employment, a Production Facility which has achieved ISO 9002 certification, Transportation and Advocacy services. Our Vision is to be a recognized leader assisting all persons with disabilities, including those with the most significant support needs, to become more independent and included as valued members of the community. Respect for the dignity and worth of each person is the driving force of this commitment. Evansville ARC is governed by a Board of Directors composed primarily of business leaders and family members of people with developmental disabilities.

Evansville ARC is located in Evansville, in southwestern Indiana, on the banks of the beautiful Ohio River with a population of over 125,000 and within three hours of driving distance of major metropolitan areas. We have an excellent quality of life including a low cost of living, little or no crime, excellent public and private schools, and a transportation system that can get you across town in less than a half hour. Enjoy a small town environment but with the cultural advantages of an urban setting!!

We offer a competitive salary commensurate with the required level experience and level of executive responsibilities the individual will assume. In addition we have a generous benefits package. Applicants may apply on line to www.evansvillearc.org or submit a resume to Vickie Warren, Human Resources Director, Evansville ARC, P.O. Box 4089, 615 W. Virginia Street, Evansville IN, 47724, FAX 812-421-8537, telephone 812-428-4500 or vwarren@evansvillearc.org.

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TASH: Public Policy In Action

Have you ever thought, "I don't like the ways things are going. I want things to change! Why doesn't *somebody* do something?"

Sadly, we soon find out that "somebody" is probably **NOT** going to do "something," and that we better step in and try to "do something" ourselves! But how to begin?

The TASH Governmental Affairs Focus (or "strand") developed for the 2001 Conference in Anaheim will meet the needs of self-advocates, family members, friends and supporters who want to make a difference!

If you are uncertain about calling on state officials or your Member of Congress, here's your chance to learn about how decisions are made, and to practice communicating about issues that are important to you.

If you have difficulty writing letters or speaking in public, we will demonstrate and practice some alternative ways to "tell your story."

The theme of the Governmental Affairs Focus this year is based on the outcome of discussions with TASH Board member Liz Obermayer, a self-advocate from Maryland. Her vision of an accessible, easy-to-understand series of workshops and activities has been supported by national disabilities leaders from TASH, ADAPT, Syracuse University and Project Leadership. The entire focus is to help participants become more effective and confident advocates. Check it out! You could become that "someone" who does "something" to make your community a better place for everyone.

* * *

The **Elementary and Secondary Education Act** recently passed by the House and Senate (H.R.1 and S.1) contain amendments that will put children and youth with disabilities in jeopardy. Specifically, both versions of the bill contain what is called "discipline" language, but in reality are provisions that allow school districts to suspend or expel students with disabilities from public school without providing any services at all. If these amendments are agreed to, they will overturn the Zero Reject (all means all) provision that has been the cornerstone of the IDEA for over twenty-five years.

Currently, the bill is "in conference." This means that Senators and Representatives appointed by their respective leaders are beginning a series of meetings to discuss differences in the House and Senate versions and to decide what to do about those differences.

It is critically important that TASH members generate letters to their Representatives and Senators from now until the Congress completes work on the Elementary and Secondary Education Act.

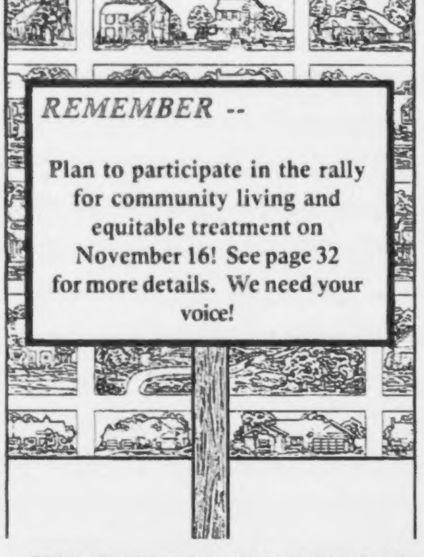
WHO: The names of your Congressional representatives can be found on the Internet at <www.thomas.loc/gov> You can also call your local library or TASH at (410) 828-8274 ext. 104.

THE MESSAGE is quite simple:

Dear (name of your Senator or Representative): Please act to remove the IDEA discipline amendments from H.R.1 during the conference on the reauthorization of the Elementary and Secondary Education Act. The issue of discipline for students with disabilities should be considered when IDEA is reauthorized in 2002. Thank you. Include your name, address, and relationship (self-advocate, family or friend of a person with a disability, educator or professional concerned with the education of people with disabilities).

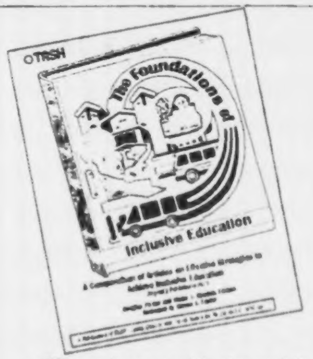
SEND TO:
The Honorable (full name of Senator) or The Honorable (full name of Representative), Rm.#, (name of) Senate Office Building or (name of) House Office Building, United States Senate
Washington, DC 20510 or
U.S. House of Representatives
Washington D.C. 20515

Please send copies of ALL letters to the TASH Governmental Affairs Director, Jamie Ruppmann. Letters may be forwarded by e-mail <jruppmann@tash.org>; fax (410/828-6706), or mail (TASH, 29 W. Susquehanna Ave., Suite 210, Baltimore, MD 21204). Jamie will deliver copies of all letters to Senators Ted Kennedy and Tom Harkin, and congressional conferees.



REMEMBER --

Plan to participate in the rally for community living and equitable treatment on November 16! See page 32 for more details. We need your voice!



The Foundations of Inclusive Education:

A Compendium of Articles from JASH

Edited by Douglas Fisher and Diane Ryndak

Foreword by Steve Taylor

Consistent with the spirit of TASH, this book of readings from *JASH* includes some of the most important articles about inclusive education that have been published in recent years. The compendium includes the following subject areas:

- ❖From Least Restrictive Environment to Inclusion: Conceptual Underpinnings and Overridding Issues
- ❖Perceptions of Inclusion and Attitudes Towards Students with Disabilities
- ❖From Facilitation of Social Interactions to Belongingness: A Change of Focus
- ❖Strategies That Facilitate Inclusion

"These JASH articles have helped shape my world view about the nature and nuance of inclusion; they illustrate important dimensions in the dynamic evolution of LRE policy."

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"The authors represented in this new resource are the most qualified specialists researching and applying strategies for inclusive education today."

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"A book rich with the basic concepts, supportive research, and change strategies critical to establishing inclusive schools."

~ Martha Snell, University of Virginia

"The Foundations of Inclusive Education explains not only the rationale, but also the practicalities of creating and maintaining inclusion."

~ Douglas Biklen, Syracuse University

"Finally, a collection of seminal readings university instructors can use to provide both contemporary and historical readings for any number of classes in special education!"

~ Jacqueline Thousand, California State University, San Marcos

This textbook is a *must* for all who are struggling with the complexities of inclusive education. Place your order now for the Fall semester!

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TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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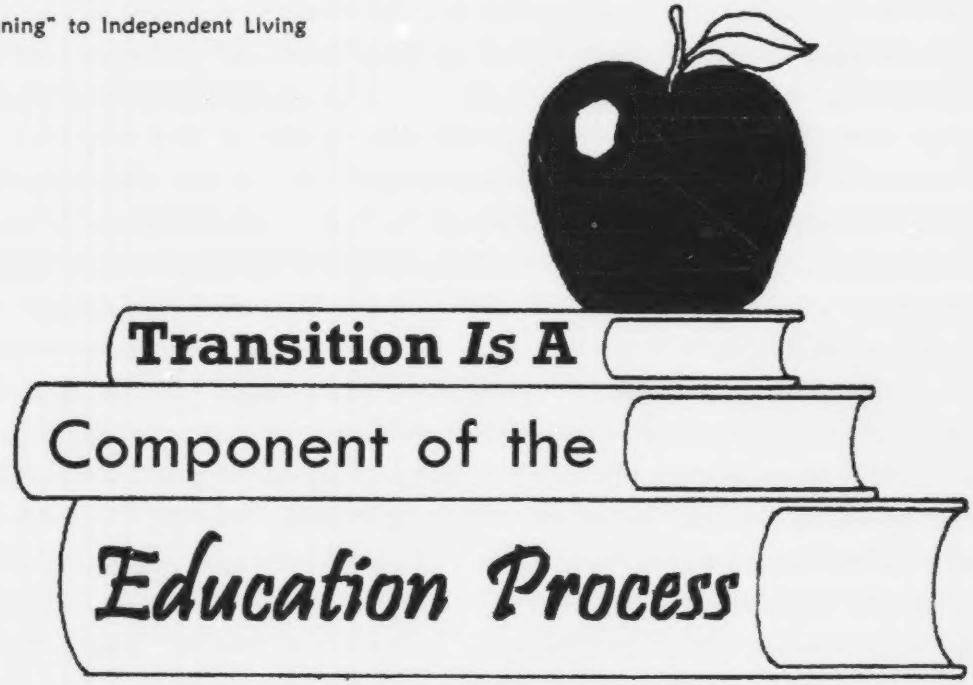
VOLUME 27 • ISSUE NUMBER 9 • SEPTEMBER 2001

TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- 2001 TASH Executive Board Election .
- Inclusion in Higher Education
- Are Students Being Prepared for Adult Lives?
- "Transitioning" to Independent Living Skills



Transition *Is* A Component of the *Education Process*

URGENT! Dated Material Inside: 2001 TASH Board Election Ballot!

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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

MISSION STATEMENT

TASH

Stretching the boundaries of what is possible;

Building communities in which no one is segregated and everyone belongs;

Forging new alliances that embrace diversity;

Advocating for opportunities and rights;

Eradicating injustices and inequities;

Supporting research and disseminating knowledge and information;

Promoting inclusive education;

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WHOM DO I CONTACT??

- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Training and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
- **For questions about the 2001 Annual TASH Conference, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- **For information on governmental affairs, call:** Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jruppmann@tash.org
- **For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- **For information on the Journal (JASH), call:** Linda Bambara, Editor-in-Chief, at (610) 758-3271, e-mail: LMB1@lehigh.edu
- **Don't forget to visit TASH's web site at http://www.tash.org**

TASH Connections is available on audiocassette, in large print, and in Braille for people whose disabilities make these alternative formats preferable. Call (410) 828-8274 ext. 102 to request an alternative format. Requests for permission to reprint material appearing in TASH Connections should be sent to: TASH Connections, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Connections Editor. Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

From the Executive Director
BY NANCY WEISS

2001 TASH BOARD ELECTIONS

It's election time and TASH needs your vote.! The ballot is included in this issue of TASH *Connections* on page 9.

The Executive Board is a group of TASH members, elected by the membership, to set policy, oversee the organization's finances and guide TASH's overall direction and goals. Four Board members will be selected through this year's election process. There is likely no more important decision an organization makes than the people it selects to guide its future.

Some TASH members have asked how the nominees for the Board are selected. Each year, a Nominations Committee is convened. This committee has broad representation across all of the kinds of people that make up TASH's membership. The Nominations Committee first looks at a grid that describes the roles that the returning members of the Board fulfill and then selects candidates based on an assessment of the types of individuals needed for diversity and balance.. This year, for example:

- Five of the 13 returning members have a history of involvement in their chapters;
- Two of the 13 returning members are parents or family members;
- Four of the 13 returning members are people with disabilities/self-advocates;
- Two of the 13 returning members represent ethnic minorities;
- Three are men; ten are women;
- Six of the 13 returning members are university professors or otherwise university affiliated;
- Six of the 13 returning members have legislative experience;
- Three have business or management experience;
- Two have fundraising experience;
- All have a strong history of TASH involvement;
- Returning Board members represent the following states: California (2), Colorado, Florida, Illinois, Maine, Maryland (2), Massachusetts, Pennsylvania, and Texas. Additionally, one Board member is from Alberta, Canada.

Since these are the criteria the Nominations Committee uses in selecting candidates for the Board, we thought it would be helpful to you to have this information in making your voting decisions.

We hope that all TASH members will participate in this year's elections. We're aiming for as inclusive a process as possible! The four candidates who are selected will be announced in the November Issue of TASH *Connections*. We appreciate your participation!

Joint Strategic Planning Session Planned for Anaheim!!

A strategic planning session will be held in conjunction with the conference on **Saturday, November 17th from 1:00 - 4:00 pm.** The purposes of this session will be to:

- Identify what the TASH committees, chapters, members, staff and Board have accomplished toward meeting the goals of the current strategic plan.
- Review and discuss the proposed mission statement and new names for TASH. A final recommendation on a new name will be made by the people attending the strategic planning session in Anaheim. It is planned that a decision on a new name will be finalized by the Board at their meeting following the strategic planning session.

All chapter officers, committee chairs, Board members and staff are invited to participate! All chapters and committees are encouraged to have at least one representative attend this important meeting. If you would like to attend (but are not a committee or chapter representative), please contact Nancy Weiss at <nweiss@tash.org> or indicate on your completed conference registration form that you plan to attend. We welcome the participation of all TASH members as space allows.

Want to have your voice heard on the new name proposals? At the conference, all members will be given an opportunity to participate in a poll to indicate your choice for a new name from the options proposed by the New Name Committee.

The 2001 Executive Board ELECTION

YOUR ROLE IN SELECTING TASH's LEADERS

One of the most important things members of any organization are asked to do is to participate in selecting members of the Executive Board. Now is the time for you to decide who will help provide critical leadership in TASH's social justice movement for people with disabilities. Many important issues and challenges face us - your participation as a voting member of TASH counts more than ever.

Four of the 15 seats on the TASH Executive Board will be re-seated at the November 2001 TASH Conference in Anaheim. The individuals who appear on this year's slate have made significant contributions in the lives of people with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 9, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by **October 12, 2001**. Please use ink and vote for four candidates. Voting for more than 4 nominees will invalidate your vote.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS:

Jacki Anderson

Jacki Anderson's ongoing commitment to include individuals with significant disabilities in all aspects of life has been readily evident throughout the three decades she has been in this field. As a classroom teacher, she spent 10 years working in the first integrated California public schools program for students with multiple disabilities, autism and other health impairments. These students, who had historically been served in institutions or segregated schools, taught her the power of teaching in natural environments, the importance of family partnerships in the educational process, and the tremendous need for both advocacy for effective services and educated support personnel.

These important lessons have been the foundation of her efforts as a trainer, researcher, and facilitator of systems change. She has over twenty-five years' experience conducting inservice training activities around the country and has taught for twenty-one years in Special Education teacher training programs at the University of Wisconsin, San Francisco State University, and California State University Hayward, where she has served as coordinator of the masters degree and credential programs in the area of moderate-to-severe disabilities since 1986.

Jacki's areas of specialization include personnel training, inclusion of individuals with significant disabilities, and positive behavior support. She has been awarded funds to pursue all of these interests via research, training, and model demonstration projects and has published the results in textbooks, chapters, and journal articles. She served as Coordinator of the California Research Institute on the Integration of Students with Severe Disabilities (CRI), Director of a series of personnel training projects addressing integration, community intensive instruction and inclusion, and as Training Coordinator for the Rehabilitation, Research and Training Center on positive Behavioral Support, A six University consortium m dedicated to developing and disseminating practical technologies for supporting individuals with behavioral challenges in inclusive school, work and community environments. Over the course of this project, she coordinated the development of a comprehensive inservice training model to establish interagency state level training teams. As a result, a network of 25 State teams is working collaboratively to provide training and technical assistance to assist local communities in building the capacity to provide effective and respectful positive behavioral supports in inclusive settings. She also serves on a variety of national, state, and local committees and advisory boards.

Jacki has been an active member of TASH since 1979 and of CAL-TASH since it was founded in 1982. She is past president of the CAL-TASH board, (board member since 1989), board member of TASH since 1998 and is currently serving as Vice President. Jacki would bring to the board an understanding of and commitment to the relationship between TASH and the chapters. She has a genuine interest in the organization's continued efforts in the areas of advocacy and the dissemination of information via the journal, newsletters and efforts to influence legislation and policy development that support the rights of individuals with significant disabilities to be active and respected members of our society.

Continued on page 5

2001 TASH Board Election

Continued from page 4

Linda Bambara

"It is truly an honor to be considered a nominee for the TASH board. I've been an active member of TASH for over 20 years, serving the TASH community in a variety of roles. Most recently I have co-chaired the Positive Approaches Committee, coordinated the research strand for several conferences, served as ex-officio board member and editor-in-chief of JASH.

In my spare time, I am an associate professor of special education at Lehigh University. My interests for both research and practice include developing and fostering the acceptance of positive behavior supports in the schools and the community, and enhancing self-determination for people with significant disabilities through both skill development and supportive environments. Additionally, I serve as executive director of Lehigh Support for Community Living, a university-based program that provides direct supports for adults with disabilities to live in inclusive community settings. Being involved in the service world and academe keeps me mindful that research must serve a social agenda, and that advocacy and research must work hand in hand.

I have been a long time TASH member because I believe in its values; values that have been shaped by the collective voice of diverse groups including people with disabilities, advocates, researchers, service providers, and families.

As a board member, my goal would be to insure that people with the most significant support needs remain in the forefront of our discussion. Those who carry the label of severe disability continue to be marginalized in all aspects of our service, misunderstood, and underrepresented by other organizations. Nationwide, other organizations have looked to TASH to set the values and direction for the support of people who continue to have little voice in this country. We must not lose sight of this most important agenda as TASH broadens its goals to address issues that affect all people with disabilities. In my view, we must continue to translate supports for people with the most intense needs, or otherwise, our system will fail to see and appreciate their full capacity.

In addition, I am committed to keeping the research agenda alive in the TASH organization. Because of its constituency, TASH is in a unique position for researchers to form partnerships with various stakeholder groups (e.g., people with disabilities, families, policy makers, service providers) to promote the most progressive, authentic, and socially minded research agenda. In addition to its advocacy, TASH must continue to support its research mission to strengthen its credibility with other organizations, shape the teaching agenda for professional development, and influence legal and policy decisions.

I will look forward to the opportunity to serve and promote TASH values to other groups outside of the organization through advocacy and research."

Tracy Knight

Tracy's allegiance to working for and with individuals with disabilities is rooted in her early family life. As the oldest child of three, the youngest of which had a significant speech impairment, Tracy was reared by a single mother in a low income area of Jackson, Mississippi. "The multiplicity of race, economic status, education and disability related experiences presented my family with unique challenges and necessitated my becoming an advocate early on."

Tracy has provided services to individuals with disabilities at the elementary, middle, high school and college level for nearly ten years. While pursuing her doctoral degree at the University of Wisconsin-Madison, Tracy participated in many activities designed to promote enhanced inclusive practices and career placement opportunities for students with disabilities in urban settings. She is currently an assistant professor of special education in the Department of Teaching and Leadership at Syracuse University. As a

Continued on page 6

2001 TASH Board Election

Continued from page 5

teacher-educator, she provides instruction on methods and curriculum for working with students with significant disabilities in diverse inclusive settings.

Based upon her collective experience, Knight has honed her advocacy and research focus to "give voice" to the experience of families in urban areas rearing children with significant disabilities. She strongly believes that equitable and effective teaching is predicated upon the degree to which educators understand, accept, and appreciate the cultures of the communities in which they teach, as evidenced by her work with several parent support groups, faith communities, and service provision agencies in upstate New York. "Families, whether nuclear, foster, or nontraditional are the most reliable constants within the lives of children with disabilities; therefore, we must honor and empower without prejudice and without question."

As a recent member of TASH, Knight is confident that her experience and continued professional and academic growth has equipped her with the skills, knowledge, and passion needed to successfully fulfill duties in alignment with the purpose and vision of TASH.

"Within the period of time I have been a member of TASH, I have continually been endowed with a passion and prowess for equity that cannot be abated. It is indeed an honor and privilege to be nominated for the board. I offer not only a unique perspective, but a pledge to work so that the veiled genius in all can be revealed."

Jorge Pineda

"My name is Jorge H. Pineda. I am from Mexico City and have been living in the United States since 1992. I am an accountant by profession and currently work at the National Council on Independent Living in Arlington, Virginia. I have been disabled since birth, and have been involved in the Disability Rights Movement since the late 1980's.

In Mexico I worked with other self-advocates to set up an organization to fight for the rights of people with disabilities. In 1991 I was invited to come to the United States to participate in a leadership development program. It was at that time that I really began to learn about all the wonderful work that was being done in this country. One of the results of my trip to the United States is that I met my wife and moved from Mexico to Berkeley, California. I became involved in numerous activities including work with Fiesta Educativa, an organization to help Latin parents who have children with disabilities. I began to learn about the many problems people with disabilities face in this country, and have been working with them to help ensure that parents are aware of their rights so that their children can obtain a quality education.

Since moving to the Washington, D.C. area, I have become involved with and am serving on numerous boards of directors and groups including the Latin American Youth Center, D.C. Statewide Independent Living Council, Next Step-Charter School, Smithsonian Institution Advisory Council on Accessibility, TASH, Fiesta Educativa, D.C. Center for Independent Living and ADAPT."

Jorge is the current Treasurer of TASH's Executive Board and is seeking a second term on the Board.

Mike Rogers

"I would like to ask you for your vote. My experience with disabilities is a personal issue because I was born with cerebral palsy. I currently work for the Department of Human and Health Services in the State of Washington, in the Department of Developmental Disabilities. For me, advocacy is not a job but a way of life. I have been involved in political issues for a long time. I became part of TASH when the conference was in Seattle, and have been at every conference since, including the self-determination conference. I currently work on self-determination systems change issues.

Some of the issues I spend time on are transportation and access to buildings and the community. I am

Continued on page 7

2001 TASH Board Election

Continued from page 6

a member of People First of Washington, and I am on the National Board of Self-Advocates Becoming Empowered (SABE).

I have experience with national issues; my experience is growing everyday. I still have things to learn. There are several major reasons I'd like to be on the TASH Board.

I'd like to give TASH members my personal insight about national policies that affect the lives of people with disabilities. My perspective is that we need to strengthen the connection between TASH and SABE and ensure that we have a dialogue with other disability organizations. This is one issue I intend to work on.

I also have an interest in making sure that policies are written so that they make sense to people, and so that everyone understands what the policy means. I think that I am a visionary. I feel like people with disabilities and people without disabilities are equals, and I want to be a part of the movement to make that happen. This organization is an organization that walks the walk and I would honored to be a part of the effort.

Patrick Schwarz

Patrick is just finishing his first term as a TASH Board member. "Through this experience, I have met some of the most determined and fun people in the world -- I would expect no less from TASH! One cannot find the spirit, passion, acceptance and sense of family TASH has anywhere else. A major part of this is our community: self-advocates and family members give this organization clear, tireless, dignified direction and keep the pulse strong."

Patrick is an adult with significant ADHD who is an Assistant Professor and Chair of Special Education for National-Louis University in Chicago. He spends much of his time preparing special educators and general educators to effectively serve all students through utilizing innovative, collaborative and school/community building teaching practices. He also serves as a part-time director for Infinitec/Empowerability, a Chicago-based not-for-profit agency that assists individuals to actualize their dreams.

Patrick previously taught public school for eight years in Madison, Wisconsin. "My teachers were Lou Brown, Ann Donnellan, Allison Ford, Jan Nisbet, pat Mirenda, Jennifer York, Pat Rogan and certainly all of my students and family members -- what an education!"

All of his spare time is spent educating generations of people who have not had the rich and critical experiences with individuals who have various significant challenges. "We all have challenges; I can attest to this firsthand. The obstacle is that much of the general public does not acknowledge their own challenges, and when they encounter someone who may communicate or get around differently than they do, they don't see the incredible human who is right there in front of them.

The reason our country has high unemployment, loss of rights and poor attitudes toward people with significant disabilities is because of the uneducated general public and lack of experiences -- not the person with the disability. The inclusion movement is the way we can do something about this. We can create an informed society. There is no doubt in my mind that inclusion is equally important for our general youth. Through inclusion, all will be informed and it will not be a big deal for our general youth community to welcome individuals with disabilities into their neighborhoods, places of employment, and friendship circles. The inclusion movement is now having great positive impact in battling attitudes, community obstacles and unemployment for people with significant disabilities."

Patrick is currently Co-Chair of the TASH Name Change Committee. "It is extremely important that the beliefs, convictions, opinions and passions of all constitutents of the organization come together to value each other's voices and stories. We are reimagining what TASH can be without losing any of the incredible legacy. Let's forge ahead, I welcome the opportunity."

"I spent some important time educating my own three-year-old niece, Haley, about diversity when she acted 'clingy' to me after seeing

Continued on page 8

2001 TASH Board Election

Continued from page 7

a person who used a wheelchair to get around. Through education and direct experience, she is now one of the best advocates around! When teaching her 'person first' language, she had the toughest time saying the word 'disability.' What comes out instead is the word 'possibility.' Her term is now 'people with possibilities.' Uncle Pat is now giving his niece a membership to TASH and inviting her on the Name Change Committee."

Jeffrey Strully

"I have been a long-time member of TASH. Over the years, I have served on the conference planning committee, as well as personally being a presenter at numerous TASH conferences.

I am currently the Executive Director of Jay Nolan Community Services, a not-for-profit human service agency located in California that provides personalized and individualized supports to people with autism and other developmental disabilities so that they can lead valued lives in the community. I have been involved with people with developmental disabilities for over 32 years in a variety of different capacities and environments throughout the United States. I have had the honor of speaking throughout the U.S., Australia and England on issues of inclusion, friendship, family-related issues, supported living, organizational change, and person-centered planning/support. In addition, I have authored several articles on inclusion and friendship with Marsha Forest, John O'Brien, and Bill and Susan Stainback.

However, most people know me as a parent. I have spoken about our family's journey for inclusion in our neighborhood school, relationships outside of school, attending college, moving into one's own home, careers, jobs and owning businesses. These are some of the issues which we have worked on and struggled with over the years. The most important issue that I have had the honor of being involved with has been the value and importance of friendships in the lives of all people. It is this subject that so many people continue to want to see happen, but it continues to be lacking in the lives of so many people.

I would like to see TASH continue to be a beacon in the professional, parent and consumer communities for those things that are important to our members such as inclusion in schools, person-centered planning, quality lives, empowerment and choice. I would hope that TASH would focus more of its efforts on the plight of adults with developmental disabilities. That is not to say that we shouldn't be concerned about what is happening in our schools. We definitely need to advocate for quality and effective education for all learners.

As an agency director, there are many issues that administering a not-for-profit organization needs to be aware of and concerned about. I would hope to bring my skills and knowledge in this area to assist the TASH central office staff as well as the Board in these matters.

Finally, TASH needs to continue to push the envelope. Whether it is generating income so that people with disabilities can accumulate wealth, attending and graduating from college, home ownership, sex, love, and marriage (maybe not in that order), friendship, or another area, I want to see TASH be in the forefront of these issues so that ALL people will lead wonderful, valued lives."

DIRECTOR OF CONNECTIONS

An innovative program of Onondaga Community Living providing personalized supports for adults with MR/DD through HCBS Waiver.

Develop, supervise and manage program and work with advisory board towards incorporation. Ensure supports are developed and delivered in compliance with Federal and State laws and policies. $250k budget. Tremendous growth potential!

Experience with MR/DD, BS/BA in Human Services with strong philosophy, supervisory, management and organizational skills.

Please forward resumes to:

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Onondaga Community Living 518
James Street, Suite 110
Syracuse, NY 13203

EOE

TASH 2001 Election of Four (4)

EXECUTIVE BOARD MEMBERS

Term of Office: 2001-2004

- OFFICIAL BALLOT -

There are four positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board members-elect will begin their terms at the Annual Board Meeting held in conjunction with the 2001 TASH Conference to be held in November in Anaheim, California.

Ballot Instructions:
You should vote for a total of FOUR nominees. Ballots containing more than four votes are invalid. Please mark your ballot in ink.

☐ **Jacki Anderson**
☐ **Linda Bambara**
☐ **Tracy Knight**
☐ **Jorge Pineda**
☐ **Mike Rogers**
☐ **Patrick Schwarz**
☐ **Jeffrey Strully**

For information about the candidates, please refer to pages 4-8 of this issue of TASH *Connections.*

Mailing Instructions:
Ballots can be returned using this postage-free mailer, or originals of the ballot can be sent in an envelope. If you elect to use an envelope, please be sure the word BALLOT is printed on the front. If you use an envelope, please do not place anything other than your ballot inside; your envelope will not be opened until the counting of the ballots.

VERY IMPORTANT:
ONLY AN ORIGINAL BALLOT WILL BE CONSIDERED VALID.
PHOTOCOPIES OR FAXES WILL NOT BE ACCEPTED.

Ballots must be received at the TASH Central Office by October 12, 2001

Mail your completed ballot to:
TASH, 29 W. Susquehanna Avenue, Suite 210
Baltimore, Maryland 21204
Attn: Ballot

✓

2001 TASH Executive Board Election BALLOT

Due in Baltimore on October 12, 2001!

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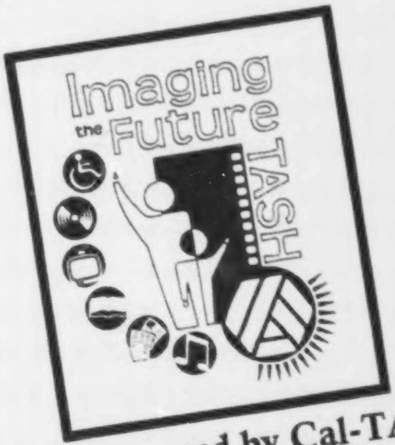

Co-Sponsored by Cal-TASH

TASH
2001 Annual Conference

"Imaging the Future"

November 14-17, 2001 ~ Marriott Anaheim
700 West Convention Way ~ Anaheim, CA 92802
Phone: 1-714-750-8000

If you can attend only *one* disability conference this year, here's why the 2001 **TASH** Annual Conference should be it! The largest and most progressive disability rights meeting in the country, the **TASH** conference features in excess of 350 workshops, interactive sessions, discussion groups, exhibits, displays and more covering the full range of cutting-edge issues related to inclusive education, supported living, self-advocacy, family issues, early childhood, communication, employment, specialized health care, assistive technology, positive behavioral supports, related services, higher education and everything in between.

We guarantee that you will leave this conference with the latest in resources, information and contacts that will help you facilitate effective advocacy, training, and research. So don't miss your opportunity to network, to learn, and to be a part of one of the most talked about disability conferences in years!

Highlights of the 2001 **TASH** Annual Conference include:

- TASH Tech Pre-Conference Workshops and Saturday Full Day Institutes covering a diverse range of topics such as *"Designing and Implementing Inclusive Curriculum: Teaching, Community, and Standards," "Civil Rights, Self-Determination and Decision Making vs. Guardianship," and "An Introduction to 'Real Futures: A Transition Training for Parents of Children with Disabilities"*
- A keynote address by Dan Keplinger, about whom the Academy Award-winning film, *King Gimp*, was made;
- *"Media Reflections of Disability Images,"* a unique media forum at which representatives of the disability, press, film, television, and advertising communities will discuss how media influences the images society holds of people with disabilities.

For additional details about the 2001 **TASH** Annual Conference, visit our web site at www.tash.org or call 1-800-482-8274 and request a copy of the conference brochure.

Laura San Giacomo to Open 2001 TASH Annual Conference

Yes, she has starred in such big screen films as Steven Soderbergh's Sex, Lies, and Videotape, and appeared in the movie, Pretty Woman, with Julia Roberts. And although she is about to begin her sixth season on the hit nighttime comedy, "Just Shoot Me." if you were to ask Laura San Giacomo about her most enduring and satisfying role, she'd instantly tell you that it is that of being a "momma." After all, says Ms. Giacomo "working for the world is all well and good, but if you're not actually being a parent then it's all a sham."

Laura San Giacomo, film actress and star of the hit NBC show, "Just Shoot Me," is scheduled to appear at the Wednesday evening Opening Reception of the TASH Conference on November 14, 2001.*

Full details on the conference can be found at www.tash.org, or call 1-800-482-8274 and request a conference brochure.

The Big Life - A Momma's Version

I became an advocate for my son when he turned three years old. By that time, I had accumulated enough stories from therapists and parents to know that both the school system and the insurance industry do not meet the more extensive needs of a child with disabilities. I decided to make a stink, start a fight, and leave a wake in our trail for other children. As a parent, one gets to experience many different templates of therapy and their benefits first-hand — all of the little gains, nuances, and milestones on a day-to-day basis.

My son and I are fortunate to have been supported by NDT (neuro-developmental therapy) therapists, conductive educators, and therapists from the MOVE (Mobility Opportunities Via Education) program. I have put into place for him a comprehensive and complimentary program for his development. In my battle with the Los Angeles Unified School District (L.A.U.S.D.), I wrote papers containing anecdotal evidence of the benefits of these programs. Although I won the battle to be reimbursed for certain of my son's therapies, this system could not open their minds or eyes to the benefits of these programs for other children. My victory for my son was labeled a "mistake" by the L.A.U.S.D., and I fought through several attempts on their part to renege on legal agreements that had been made through a mediation process.

By the time my son was five, the Individual Education Plan process had created 54 goals for him, and we had been through five I.E.P.s, two informal hearings and two mediations. It seems incomprehensible that the special education and physical therapy departments are so naïve, ignorant, and arrogant about the needs of our children. I'm not implying that one hundred percent of services be reimbursed; I'm asking the system to look at alternative and, in some cases, less costly templates for greater function.

I started contributing money to organizations that I thought were making a difference for children. On my own and with the help of the producing entities of *The Hollywood Squares*, I have been fortunate enough to make donations to three organizations: MOVE International, L.A. Therapy For Children, and The Chime Institute For Children With Special Needs. I have participated in numerous fundraisers for a variety of charities on various levels either through my attendance and guest speaking, procuring items for silent auctions and purchasing items in bidding wars, and donating funds for entertainment. These charities are: The Lilly Claire Foundation for children and adults with Williams Syndrome; Best Buddies, an organization pairing typical and special needs high school, college, and young adults; Shane's Inspiration, an adaptive playground where children of all abilities can play together; SERT- Special Equestrian Riding Therapy (horseback riding therapy for children with special needs); UCLA early intervention program (a birth through 3-year-old early intervention program); MOVE International, a therapeutic template for children with physical disabilities; The Elizabeth Glazer Pediatric AIDS Foundation, helping young children with AIDS and their families; City Of Hope, helping families with members diagnosed with

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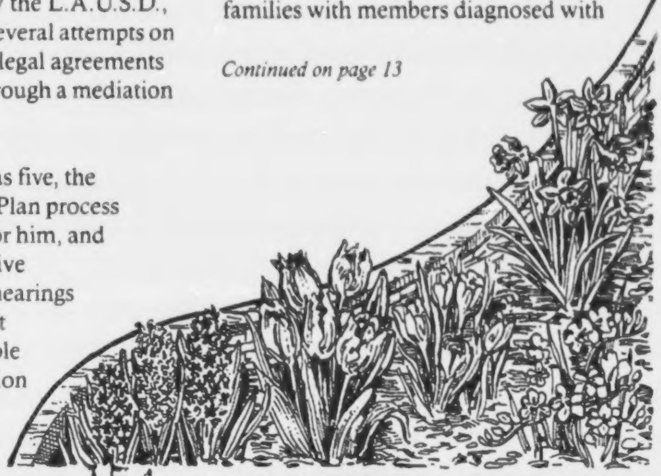
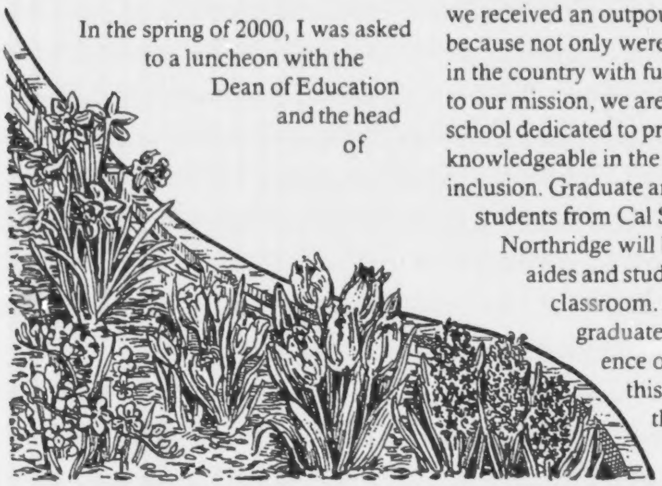


Laura San Giacomo to Open 2001 TASH Annual Conference

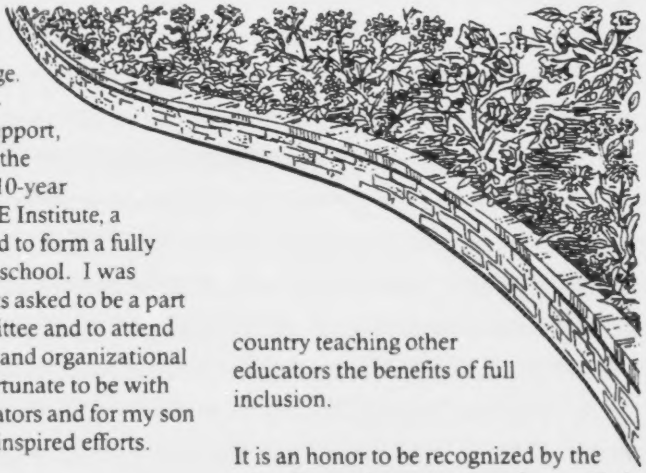
Continued from page 12

cancer; My Friend's Place, helping homeless and runaway teens on the streets of Los Angeles; Covenant House, helping homeless and runaway teens on the streets of New York and Los Angeles; as well as the myriad of photo requests that come directly to me at my place of employment.

One of the contributions that I am most proud of is the time that I have contributed to the public service announcement in "The More You Know" series on the subject of inclusive education. Because of Roz Weinman's generous spirit, my suggestion of developing a series of service announcements was met with whole-hearted enthusiasm. After sharing my research with her on inclusive education and sending my own draft of the spot, her staff wrote an eloquent and simple message to parents. The piece was recognized by the Media Access For Disabilities Awareness Organization in their awards ceremony in the Fall of 2000. Because these simple messages are shot so beautifully and aired during prime viewing hours, it's not only visually appealing, but a simple, straight forward message tends to teach a lot of people.



In the spring of 2000, I was asked to a luncheon with the Dean of Education and the head of Special Education of California State University, Northridge. Because of such overwhelming parental support, the desperate need in the community, and the 10-year success of the CHIME Institute, a movement had started to form a fully inclusive elementary school. I was among several parents asked to be a part of the steering committee and to attend the initial conceptual and organizational meetings. I felt so fortunate to be with these dedicated educators and for my son to benefit from their inspired efforts.



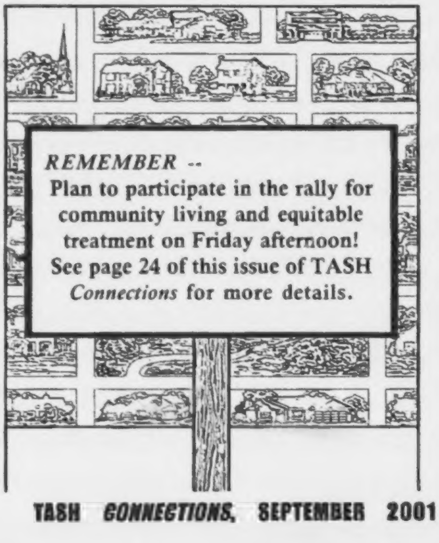
Currently we are in the final draft of our charter proposal and searching desperately for a temporary space for the school. We are also applying to various foundations for grants for adaptive playgrounds, technical support for all of our students, equipment for classrooms, and various other expenses not provided to a charter school by the district. Not only does the mission statement of the charter school incorporate inclusive education, but it also emphasizes academic excellence, comprehensive evaluations of all students, conscientious citizenship, and an ethical curriculum which includes life learning. There will be 2-4 children with disabilities per classroom, a percentage that directly reflects the population.

While attending the Charter School National Conference in Washington DC, we received an outpouring of attention because not only were we the only school in the country with full inclusion central to our mission, we are also a teaching school dedicated to producing teachers knowledgeable in the benefits of full inclusion. Graduate and undergraduate students from Cal State University, Northridge will be participating as aides and student teachers in the classroom. As student teachers graduate with the experience of participating in this elementary school, they will go out to all parts of the country teaching other educators the benefits of full inclusion.

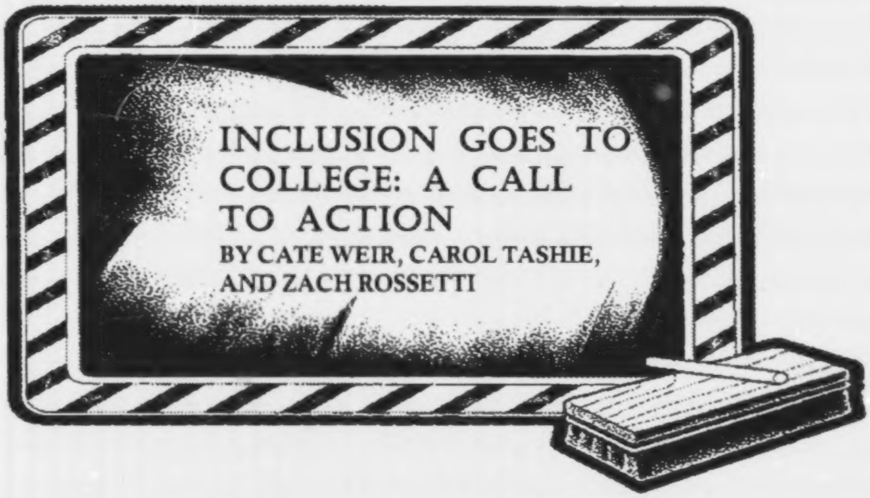
It is an honor to be recognized by the school's steering committee for my "baby steps" in trying to address the needs of families of children with disabilities. My main reason for doing this "speaking out" is not only for the benefit of my son, but to be able to make a difference to another mother in need. I am grateful for the ground-breaking fights that mothers, advocates, and lawyers have been consumed by over the past 30 years, and it is a conscious decision on my part to try and take the world another step.

I am honored to be a part of the 2001 TASH Annual Conference, helping all of us, together, to work toward "*Imaging the Future*."

*Ms. Giacomo's appearance has been confirmed, however, her participation is contingent on her filming schedule.



REMEMBER --
Plan to participate in the rally for community living and equitable treatment on Friday afternoon! See page 24 of this issue of TASH *Connections* for more details.



INCLUSION GOES TO COLLEGE: A CALL TO ACTION

BY CATE WEIR, CAROL TASHIE, AND ZACH ROSSETTI

For all of her life, Kathy was told her disabilities would prevent her from achieving academic goals, especially the pursuit of a college education. Her high school years were spent sitting in special education classrooms, excluded from the college preparatory classes she wanted to attend. "College is out of the question," she was told. Her teachers and guidance counselors encouraged her to be "realistic" about her future plans. But Kathy wouldn't listen.

When she was 27 years old, she contacted the local college and said, "I want to take some classes. " And now, two years later, she is pursuing her college degree at the New Hampshire Community Technical College at Manchester. The college has provided accommodations, tutorial support, and assistive technology that assist her in achieving her goals. Vocational rehabilitation provides support in goal setting and in purchasing equipment she needs. The local adult support agency provides help at her home with class assignments. The Assistive Technology Low Interest Loan program lent her money to buy a computer. And most importantly, Kathy has provided the energy, hard work and unwavering commitment to her goal. Together, this collaboration works to support Kathy's dreams.

> *"When I was born, they told my parents I should be in an institution. Well, today, I am in an institution, but it's an institution of higher education."*

Jesse is also a college student, studying Veterinary Technology. In many ways, she is a typical college student. She studies hard, worries about exams and struggles with the Latin terms in animal anatomy and physiology. But if you ask her about her experiences, you will realize she is also, in many ways, unique.

Jesse has many labels that have led many people to believe she doesn't belong - and never would succeed - in college. But she is succeeding in her goal to attend college and earn an associate's degree. Jesse is reaching her goal with the help of hard work, family support, an individually designed major that fits her career goals, and an academic advisor that knows her potential and is working creatively with Jesse and the college faculty. In her own words: "When I was born, they told my parents I should be in an institution. Well, today, I am in an institution, but it's an institution of higher education."

In the past few years, individuals with labels of severe disabilities and their families have been declaring that access to college must be a choice for everyone. Advocates like Kathy and Jesse and others have challenged society's prejudices and taken their rightful places on college and university campuses throughout the country. But just as it was when students with severe disabilities moved from fully inclusive elementary schools to high schools that were less than welcoming, there remains the perception that higher education is "unrealistic," "too difficult," or even a "waste of time and money" for some people.

Although it is widely acknowledged that higher education is critical in terms of employability and lifelong earnings, it is still commonplace to exclude people with labels of severe disabilities from college, based on out-dated notions of disability and achievement. But is it reasonable and just to advocate for full inclusion in elementary and high schools, and still allow college to remain outside the grasp of so many? In other words, does full inclusion go to college?

BACK
TO
SCHOOL
COLLEGE

The struggle for educational equity for students with disabilities has been expanding since the beginning — from the front door to the classroom door, from elementary school to high school, from social integration to high academic expectations. For twenty-five years, powerful advocacy has taken place to assure that all students have real places in their public schools. But, in that same period of time, rarely has college been discussed. For many, there continues to exist a belief that individuals with severe disabilities could never be successful in college. This misguided reality, based on out-dated assumptions about what labels mean in terms of intelligence and competence, is often coupled with paternalism and motivated by a desire to protect people from what is imagined to be certain failure. These factors work together to make dreams of college seem silly, unrealistic, and even dangerous for certain people.

Continued on page 15

INCLUSION GOES TO COLLEGE: A CALL TO ACTION

Continued from page 14

In fact, the language of the ADA, specifically the clause regarding 'otherwise qualified,' has been used to exclude many students with severe disabilities from colleges and universities of their choosing.

Along with the assumptions and fears about disability and college success, there also exists a passive approval of the entrance criteria colleges use to judge suitability for acceptance. These criteria continue to be based on narrow definitions of intelligence, potential, and academic success. Therefore, when a high school algebra teachers claims that a student with severe disabilities doesn't belong in her classroom, the challenges are loud and sustained. But when a college admission counselor advises the exact same thing, there is curious silence. It is time to dispute exclusionary practices at colleges and universities.

The passage of the Rehabilitation Act of 1973 made it illegal for the vast majority of colleges and universities to discriminate on the basis of disability. However, it was not until the passage of the Americans with Disabilities Act in 1991 that most post secondary institutions began to take this responsibility seriously. As a result, the percentage of students with disabilities attending college has increased, from just 2.6% in 1978 to 11% in 1997. However, this increase reflects primarily those students with disabilities who still fit the mold of a "traditional" college student. In fact, the language of the ADA, specifically the clause regarding "otherwise qualified," has been used to exclude many students with severe disabilities from colleges and universities of their choosing.

One of the challenges to this call to action is that colleges and universities, by nature and design, have historically been exclusive places. Higher education has been used throughout time to "separate the wheat from the chaff," and to educate only a "worthy" subset of our citizens. But why do we need to continue to accept this? President Clinton, in his 1997 State of the Union address, pronounced ". . . every 18-year-old must be able to go to college, and all adults must be able to keep on learning." Those of us who advocate full inclusion for all citizens must begin to challenge this exclusive domain.

In order to ignite this change, we must also challenge the attitudes of paternalism and protectiveness that limit people's choices and chances, at the cost of real self-determination. Assumptions about ability and capability have led many of us to advise students to avoid college, because we "know" how hard college is and we "believe" they don't have what it takes to succeed. Although this may be seen, by some, as a "kindness," oppression in the name of protection is still oppression.

As a result of the activism of individuals and their families, as well as the work of a few federal initiatives, the doors to a college education are beginning to crack open. There are students with labels of severe disabilities who are pursuing their educational dreams and, in so doing, shattering many of society's assumptions. However, in our haste to move forward, some dangerous missteps are occurring. Some colleges are designing or hosting programs that do little more than move the special education classroom to the college campus. Some school districts are developing partnerships with one or more community colleges to run "transition programs" for their post-graduates with severe disabilities. Some colleges are allowing students with severe disabilities access to nonacademic classes, with little regard for student choice, grades, or college credits. And while some may view these things as "a good start" or "better than nothing," it is indeed a slippery slope down which dreams of inclusive college communities can easily slide. We must learn from the past and refuse to support the development of special classes or programs on college campuses, for they, like special education classes in public schools, will eventually need to be dismantled in favor of real inclusive choices.

It is time to recognize that the values and beliefs of inclusion — labels are not informative, disability is a social construct, and all of us are enriched by a diverse community — apply to higher education as well. We must work to support people with severe disabilities in the attainment of their goals and acknowledge that, in fact, inclusive education means college, too!

This article is supported in part by the U. S. Department of Education, Office of Special Education and Rehabilitative Services grant #HO78C60074 and the Office of Post Secondary Education grant #P333A990035. The contents of this paper do not necessarily represent the policy or position of the U.S. Department of Education.

Comments about this article may be directed to Carol Tashie at the University of New Hampshire, Institute on Disability/UAP, 10 Ferry Street, #14, Concord, NH 03301, or you may send an e-mail to ctashie@cisunix.unh.edu

BEST COPY AVAILABLE

The Foundations of Inclusive Education:

A Compendium of Articles on Effective Strategies to Achieve Inclusive Education

Edited by Douglas Fisher and Diane Ryndak

Foreword by Steve Taylor

Consistent with the spirit of TASH, this book of readings from *JASH* includes some of the most important articles about inclusive education that have been published in recent years. The compendium includes the following subject areas:

- ❖From Least Restrictive Environment to Inclusion: Conceptual Underpinnings and Overridding Issues
- ❖Perceptions of Inclusion and Attitudes Towards Students with Disabilities
- ❖From Facilitation of Social Interactions to Belongingness: A Change of Focus
- ❖Strategies That Facilitate Inclusion

"These JASH articles have helped shape my world view about the nature and nuance of inclusion; they illustrate important dimensions in the dynamic evolution of LRE policy."

~ Anne Smith, U.S. Department of Education

"The authors represented in this new resource are the most qualified specialists researching and applying strategies for inclusive education today."

~ Norris Haring, University of Washington

"A book rich with the basic concepts, supportive research, and change strategies critical to establishing inclusive schools."

~ Martha Snell, University of Virginia

"The Foundations of Inclusive Education explains not only the rationale, but also the practicalities of creating and maintaining inclusion."

~ Douglas Biklen, Syracuse University

"Finally, a collection of seminal readings university instructors can use to provide both contemporary and historical readings for any number of classes in special education!"

~ Jacqueline Thousand, California State University, San Marcos

This textbook is a *must* for all who are struggling with the complexities of inclusive education. Place your order now for the next semester!

==

☐ Yes, I would like to order 1-25 copies at $19.00 each (member rate); $23.00 (non-member rate)
26-50 copies at $16.00 each (member rate); $21.00 (non-member rate)
50+ copies at $13.00 each (member rate); $16.00 (non-member rate)

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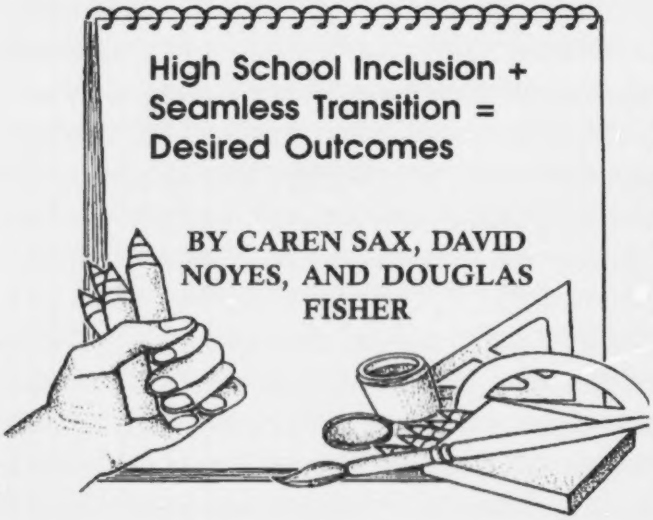
High School Inclusion + Seamless Transition = Desired Outcomes

BY CAREN SAX, DAVID NOYES, AND DOUGLAS FISHER



Schools are being held accountable not only for the outcomes of typical students, but for those of students with disabilities as well. The expectation is that education should contribute to the preparation that all U.S. citizens need to fully and meaningfully participate in public life. This right is deeply embedded in U.S. law and heritage; it is an inalienable right (Gilhool, 1976). It is the responsibility of public education to help ensure that all American citizens, whatever their disabilities, are afforded an equal opportunity to actively participate in all community activities, events and opportunities.

Outcome-based questions have become a standard for evaluating the effectiveness of education. For example, "Has the school system done its job in preparing students with disabilities for adult lives, which involve active participation in work, home, educational and social environments?"

Data from the National Longitudinal Transition Study (Wagner, 1993), as well as other studies (e.g., La Plante, Kennedy & Turpin, 1996; Malakpa, 1994; Mithaug, Moriuchi, & Fanning, 1985) have documented poor post-school outcomes for students with disabilities. In addition to high drop out rates (overall 58%), these students often exit into low-wage jobs, have higher arrest records (44%), and are unemployed in vast numbers (60%). It is estimated that approximately 75 percent of adults with a label of "severe" disabilities and 92 percent of adults with a label of "profound" disabilities are unemployed (La Plante, Kennedy, Kaye, & Wenger, 1996). According to Wagner (1995) and Blackorby and Wagner (1996), only 17% of students with multiple disabilities were employed or received postsecondary education during the first five years after exiting school.

Wehlage and Rutter (1986) argued that it is the school, and not the student, that must change if appreciable progress is to be made. It has been hypothesized that two significant changes to the service delivery system could impact the employment outcomes for students with disabilities - inclusive education and seamless transition from school to career (Certo, Pumpian, Fisher, Storey, & Smalley, 1997; Fisher & Sax, 1999; Gerry & Certo, 1992; Katsiyannis, de Fur, & Conderman,1998; Lichtenstein, 1993; Meyer, 1994; Phelps & Hanley-Maxwell, 1997; Szymanski, Hanley-Maxwell, & Asselin, 1992).

First, inclusive education has been defined by the National Association of State Boards of Education (NASBE, 1995) as follows: At its core, inclusion means that students attend their home school along with their age and grade peers. A truly inclusive schooling environment is one in which students with the full range of abilities and disabilities receive their in-school educational services in the general education classroom with appropriate in-class support.

Second, a "seamless transition" describes the use of resources from school and post-school systems (e.g., Department of Rehabilitation, Department of Developmental Disabilities) to share the costs of supporting a student-driven approach to choicemaking and transition planning related to developing careers, community living skills or opportunities, and postsecondary education for students about to age-out of their local public school system (Certo & Sax, 1999; Sax, 2000).

Following graduation and the end of public school responsibility, these systems share the costs of maintaining and expanding work and non-work preferred activities seamlessly on the first day after this formal exit. In other words, a student's last day in public school looks no different from the first day supported by adult service delivery systems.

Given the access to both inclusive education and a seamless transition, what are employment outcomes for students with significant disabilities? This article compares the outcomes for students with significant disabilities aging out of public school who experienced both inclusive education and a seamless transition with those who did not.

Method

Participants:

District. This district was a medium sized school district in Southern California. The total enrollment is just over 21,500 students in grades 9 to 12. Of those students, 78% are white, non-Latino; 16% are Latino; 5% are African-American; 5% are Asian-Pacific Islander; and 2% are Native American. Every school in the district has at least 9 different languages represented, and one school has 17. The district has developed Individual Education Plans (IEP) for nine percent of the students.

Students. All students from this district who met the California definition of "severe disability" and who were exiting from the public school system were selected for this study. This resulted in

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High School Inclusion + Seamless Transition = Desired Outcomes

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the identification of 33 students. Two of the 10 high schools in the district participated in a transition service integration planning process and provided special education services to high school aged students in general education classes. A total of six students transitioned out of these two schools during the year of the study.

The remaining 27 students attended one of the remaining eight high schools and did not experience a seamless transition but were mainstreamed in some general education classes such as English, art, physical education, and music. This geographic selection process ensured that there were students in both the target and comparison group who had similar types of disabilities and level of support needs.

Data Collection and Analysis

During the week following the end of the school year, a school district employee asked the primary advocate teachers for the 33 students with significant disabilities about the transition process. The following information was logged for each student: seamless transition (last day of school mirrored first day of adult program), adult program provider, and location of adult program.

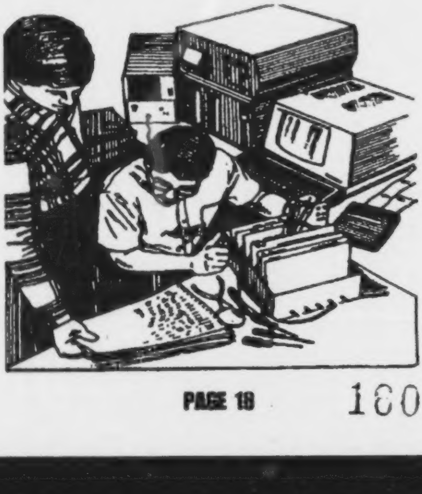
Two months later, this school district employee contacted the adult service providers and requested the following information about the 33 students: job, wages, hours worked per week, and types of integrated activities in which the individual participated during non-work hours. The data were provided to us on code sheets. We did not have student names or adult service provider identities matched with the student data. However, the data were disaggregated by target group (those who were included and participated in the transition service integration project) and comparison group. The data was reviewed and summarized accordingly.

Findings

The data indicate that students with significant disabilities who experienced inclusive education and a seamless transition entered their adult lives well situated for success. Four of the six students in the target group experienced a seamless transition, meaning that there had been significant coordination between the public school system and the adult service delivery system such that the student did not experience a disruption in services.

For example, the school system contracted with direct service personnel (e.g., job developer, job coaches) from the adult service delivery system during the student's final year of public school service (typically when the student was 21 years old) so that the same staff were consistent post-transition. Similarly, students were scheduled according to their work and non-work activities departing from the traditional school calendar and time frames.

For example, one student's employment required that he work during late afternoons and often on holidays. The integrated work environments and non-work activities were organized during person-centered planning sessions in which the student, his or her family and friends, school personnel, and adult agency staff were all present. Thus, the day after the termination of public school services did not vary greatly from what the student had been experiencing.



None of the comparison group students experienced a seamless transition. These students often visited the adult program or sheltered workshop in the weeks prior to the end of public school services. However, the staffing patterns, environments, and expectations changed dramatically when school-based services ended. For example, on the Tuesday following the completion of school-funded services, these students rode different buses on new routes, met new support staff who often did not know the student's goals, and faced unfamiliar environments in which to work. Most difficult for many of these students was the fact that the adult agency had to "start over with assessments" as they became acquainted with the students.

In terms of employment outcomes two months after leaving school, students who experienced inclusive education and seamless transition fared well. While the actual numbers of students are low, average wages and hours per week worked are consistently higher for the target group of students. These results stand out in stark contrast to the national outcome of employment and/or postsecondary education within the first five years after exiting school, cited earlier.

Interestingly, the types of integrated employment options were similar for the two groups, but students in the comparison group were less likely to access those jobs given that they were placed in sheltered workshops. The sources for the jobs held by students in the target group were more varied and included recommendations by high school peers. In addition, students in the target group were more likely to engage in integrated activities during their non-work hours. These activities included community college and adult school classes, recreation and fitness centers, and community stores and services.

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High School Inclusion + Seamless Transition = Desired Outcomes

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Discussion

The purpose of this study was to review the outcomes for students who experienced inclusive education and a seamless transition. More specifically, we were interested in learning if students with significant disabilities who experienced inclusive education within academic classes were at risk of limited options for their adult lives. While the sample was small and we encourage a cautious review of the findings, the data suggest that no harm was done and, in fact, the outcomes for the target students in this study were better than the outcomes for other students in the district in both work and non-work activities.

We believe that the results were influenced by two variables. First, over the course of their high school years during which they attended general education classes, the target students developed a number of skills, relationships, and behaviors that may have increased their employability. In addition to the curriculum and content which is beyond the scope of this study, students were expected to arrive on time, engage in social exchanges, and attend to instructions in their high school classes. In terms of relationships and peer support, students with significant disabilities in general education classes experienced a wide range of friendships. As typical high school students began their part-time jobs during their junior and senior years, they often informed the special educators of jobs at their place of employment. These job recommendations were invaluable.

As school staff and adult providers talked with one another, worked together, and shared vital student support information, they were able to individualize supports, create workplace accommodations, and implement consistent behavioral support plans. This arrangement significantly minimized the disruption students typically experience when transitioning from the public school system to the adult provider network.

Thus, we believe that access to general education classes had a significant impact on the integrated work outcomes experienced by the target students. It is important to note that the comparison students experienced a segregated academic curriculum and a significant number of hours spent in homogeneously-grouped community-based instruction during their high school years (age 14-18), and the vast majority of them transitioned into a sheltered workshop.

The second variable we believe was important was the seamless transition planning that occurred for the target students. As school staff and adult providers talked with one another, worked together, and shared vital student support information, they were able to individualize supports, create workplace accommodations, and implement consistent behavioral support plans. This seamless transition service delivery model provided students and their families with an entire year to evaluate the appropriateness of the adult agency and its services. This arrangement significantly minimized the disruption students typically experience when transitioning from the public school system to the adult provider network.

Conclusion

Although the number of students served in this pilot study was small, the findings represent all of the students with significant disabilities who aged out of the 21,500-student school district. Based on these findings, we believe that school systems can prepare students with disabilities for quality adult lives. Further, the outcomes for the target group of students demonstrate that the historical underemployment and unemployment of individuals with significant disabilities can be systematically addressed.

Two of the important factors in achieving these outcomes are access to: 1) general education classes, curriculum, and peers; and 2) a seamless transition that connects public school services and those of the adult service system.

Caren Sax, David Noyes and Douglas Fisher are affiliated with San Diego State University. Comments regarding this article may be directed to Douglas Fisher, Interwork Institute, San Diego State University, dfisher@sdsu.edu

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Now in its second year, the World Congress & Exposition on Disabilities (WCD) presents a comprehensive forum to educate, inform, and provide a useful exchange of ideas for persons with disabilities and special healthcare needs, as well as for family members, caregivers and those who work in the disabilities field. The event, scheduled for September 28 - 30 at the Georgia International Convention Center in Atlanta, is organized by H.A. Bruno, LLC.

The conference portion of the show, comprised of over 65 seminars, is produced by the EP Foundation for Education, Inc., a 501(C)3 not-for-profit organization. CME and CEU accreditation is available for many disciplines. Sessions on adapted physical education are sponsored by PALAESTRA magazine and the American Association for Active Lifestyles & Fitness (AAALF). Attendees will also have an opportunity to examine the latest products and services from more than 250 exhibitors representing pharmaceutical, computer, automotive, mobility, personal care, insurance, nutrition, and travel industries.

Special features will again include a career fair, a sports and recreation activity center sponsored by McDonald's Corp. and U.S. Disabled Athletes Fund, and an assistive technology learning center. For more information on WCD, visit www.wcdexpo.com or call 877-WCD-EXPO

Transition Is a Component of the Education Process

BY RICHARD L. ROSENBERG
and
BONNIE BOLTON

The Whittier Area Cooperative Special Education Program (WACSEP) a cooperative of seven participating school districts in the greater Whittier, California area serves middle school, high school, and young adult age students with disabilities. In compliance with IDEA's requirements for Transition, services are provided both at the school site level for students ages 14 and older and through a regional Transition Program for students ages 18-22. Transition services follow a student from age 14 until graduation.

The Transition Program includes students with severe disabilities and is designed to provide instruction in the activities of daily living, career and vocational skills, general community skills, and supporting those student who are working towards a diploma by age 22. These transition services are available to students from the Whittier Union High School District and El Rancho Unified School District.

The Transition Program was established as a community based program with seven life domains as the foundation. The seven domains are identified as:

1. Vocational
2. Recreation / Leisure
3. Domestic / Independent Living Skills
4. Community / Consumers
5. Community / Mobility
6. Communication
7. Behavior

Independent Living Skills and a Functional Vocational Evaluation

Transition Services has evolved within Whittier Area Cooperative Special Education Program (WACSEP) over the past 19 years. As the staff reflects on the 19-year history of the program, the highlight for staff has been to listen and hear each student in assisting them to reach their goals and dreams. Their goals and dreams have always been unique; therefore, services need to be crafted to meet their needs rather than services based on staff assumptions, family expectations, or current curriculum. Students attend their IEP meetings and give input into goals and objectives. The goals and objectives drive the program. WACSEP has created a means for staff to work on a protocol in order to develop meaningful Individualized Transition Plans (ITP). The protocol includes review of the student history, current interest inventories and vocational evaluations, student interview, parent/family interview, and working with the teaching and support staff to create a meaningful ITP that will be reviewed on a regular basis, updated each year, and modified as necessary to support the student moving from school to adult life.

The Whittier Transition Program has always made work a high priority for students. This has proven to be a very important turning point in the student's life as he/she moves from the comprehensive inclusive high schools to adult life. In addition, the relationship with the community colleges has also been valuable. Students within the Whittier Area Cooperative participate in integrated high school programs and work towards their diploma. The Transition services are available to those students who need the additional support to complete their Individualized Transition Plans (ITP). Occasionally some students are working towards completing their diploma.

The Transition Program for students ages 18-22 has been provided to the students on the adult education campus. This provides the opportunity to establish age appropriate peers for these students. On the adult campus the students have access to adult and vocational school classes, as well as opportunities at break and lunch to interact with other adult students. In addition, the adult school campus is centrally located and accessible by public transportation, and within walking distance to many jobs and community activities.

The mission statement for the Transition Program is:

To empower individuals with disabilities to maximize the quality for their lives through employment, inclusion, and interdependence in their home communities while transitioning from school to adult life.

Following is an individual story, as well as a story about a group of students who have been working at Old Navy, a clothing store, for two years.

Thomas is a student receiving transition services from Whittier Area Cooperative. He has significant physical challenges and has had some challenges controlling his body and language. Thomas has had great success utilizing facilitated communication. Thomas, his family, the vocational counselor, and the staff met individually and then collectively to create the Individualized Transition

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Program (ITP) for Thomas. Thomas is working toward a high school diploma and it might take an additional year or two to earn all the necessary credits. After two additional years of high school Thomas may continue to work on his diploma, as well as join the staff and students in the Transition Program for his last two years. During those final two years as he works on his diploma, he will also work on the necessary community and vocational skills to complete his transition from school to adult life. Thomas and the team are continually asking the question: Are Thomas' IEP (Individualized Education Plan) and ITP (Individualized Transition Plan) meeting his needs? Are they appropriate for his future goals and objectives? This constant questioning and working with the families and staff is one of the strengths of the Whittier Area Cooperative Special Education Program (WACSEP).

The following was an agenda for Thomas' team meeting, which included Thomas and his family:

- Where does Thomas want to be after high school? How can we all work to get him there?
- What supports do we have to help put into place in order for Thomas to access the regular bus?
- Help Thomas to create a balance of academics and quality of life at high school and beyond:
  - Means of getting a diploma: Process; Value; and Outcome
  - Means of communicating and developing relationships: Typing; Writing; Facilitated Communication
- Help Thomas to identify and access Transition Services:
  - Functional Skills development; Communication; Behavioral needs; Personal Grooming and Hygiene
- Where will Thomas want to live after school? What adult services will be available?

The second example of the Transition Program at work is that of a group of students who have been working at Old Navy, a clothing store, for two years. The students have significant challenges and through augmentative and alternative communication have requested to work in retail sales. The students work three days per week for three hours per day. The jobs that are completed with the help of a job coach is to assist with the shipping and receiving, light maintenance, cleaning and organizing the shelves, folding clothes, and placing clothes on hangers. Some of the students have progressed to customer service, including assisting customers in the dressing room.

One area that is a high priority of the Transition Services of WACSEP is self-advocacy and understanding one's rights. One's ability to advocate for what he/she truly wants — not just pleasing one's parents or teachers, but really stating what he/she desires to do when he/she leaves school — is crucial. Many of the students have not had opportunities to dream and explore the various options for his/her future.

Self-advocacy is the ability to speak up and receive supports from others as they become more independent. The Whittier Transition Program offers self-advocacy groups that are either facilitated by peers and/or staff. The goal is for the students to feel comfortable in sharing their concerns and issues and become confident in advocating for their desired outcomes. Those participants in self-advocacy groups work on their own or with a partner to be able to:

❖"Speak" for themselves;
❖Solve problems and make decisions;
❖Know one's rights and responsibilities;
❖Contribute to the community;
❖Accept one's differences;
❖Deal with labels and prejudices;
❖Increase self-awareness; and
❖Solve common problems.

Many teachers and parents see self-advocacy as a threat. In reality, it is one of the most effective skills supporters can help students to develop.

Summary

Implementation of the Transition Services part of IDEA 1997 requires teamwork between educators, parents and the student for whom the Individualized Education Plan (IEP)/Individualized Transition Plan (ITP) is developed. More than an activity of filling out forms, Transition Services should consistently push the IEP team to look to the future and to incorporate the future plans into attainable short-term goals. The Whittier Area Cooperative seeks to not only provide services to students with disabilities to achieve academically, but to become productive members of their families and home communities.

Transition is a multifaceted component of the educational process. The student is reaching the age of majority; the family is dealing with the change in perception of their son or daughter from child to adult. This process of change and growth begins in early childhood with that first graduation from early intervention services and continues past the window of time that the student will be in public school. Transition Services at the middle school and high school level, appropriately planned and implemented, prepares

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the student and family to begin yet another new stage of life — adult life — in the home and in the community.

Richard L. Rosenberg, Ph.D. is the Lead Vocational Coordinator and Bonnie Bolton is the Transition Program Specialist for the Whittier Union High School District.

For more information about the Whittier Area Cooperative Special Education Program, please contact Whittier Union High School, 9401 South Painter Ave., Whittier, CA 90605, (Phone) 562-698-8121 ext. 1250, or send an e-mail to <Richard.Rosenberg@wuhsd.k12.ca.us> or <Bonnie.Bolton@wuhsd.k12.ca.us>

IMPORTANT NOTICE: TASH Tech Cancellation

The following TASH Tech Session has been cancelled:

T-7 Creating Inclusive Childcare Settings

We apologize for any inconvenience. There is an array of outstanding TASH Techs and Saturday Institutes scheduled at this year's TASH Annual Conference. For a complete listing, visit our web site at www.tash.org; see the July/August 2001 issue of TASH *Connections*; or call 1-800-482-8274 and request a copy of the conference brochure.

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❖Celebrants will be joined by Cal-TASH, Tom Gilhool, Max Lapertosa, Barbara Ransom and Judy Grant of PILCOP as we rally on behalf of the groundbreaking *Sanchez* case filed in California. This case seeks to ensure that people who work in community settings are paid as much as people working in institutions and nursing homes.

Meet and greet the families and self-advocates who have brought about the *Sanchez* action and add your voice to theirs in solidarity for the cause of community! Co-sponsored by Cal-TASH, DREDF, and PILCOP.

FRIDAY, NOVEMBER 16, 2001

Activities will begin at 12:00 noon in the Ballroom of the Marriott!

Resource Review: Promoting Friendships, Community Connections, and Membership

This resource review highlights materials that provide many examples of strategies to promote and support community connections, and offer discussion of the challenges and complexities of community-building. It is taken from a larger information package on "Promoting Friendships, Community Connections, and Membership" produced by the Center on Human Policy.

TITLE: Friendships and community connections between people with and without developmental disabilities
AUTHOR: Amado, Angela Novak (Ed.)
PUBLICATION INFORMATION: 1993, Baltimore: Paul H. Brookes Publishing Co.

This book contains chapters that discuss a wide variety of critical issues related to friendship and people with developmental disabilities. It is acknowledged that "supporting friendships can be fragile, delicate, magical, and sensitive work. It is not work that easily fits into formalized systems and agency patterns" (p. 373). Authors discuss dilemmas and challenges related to this. The book is divided into three sections: (1) dimensions of friendships, (2) stories of friendships and (3) strategies for building friendships. Chapters in the first section include an introductory piece that discusses dimensions of friendship, issues of attraction and power, and context of community; loneliness; intimacy and sexual relationships; the gendered context of friendships; and friendships between "staff" and "clients." The second section contains stories of friendship written by people with disabilities, parents, and advocates from within and outside of the service system. Finally, chapters in the third section offer important strategies based upon focused efforts to assist people to form friendships and connections at work, in community associations, and within the community at large.

TITLE: Amistad: Stories of Hispanic children with disabilities and their friendships
AUTHOR: Beach Center on Families and Disability
PUBLICATION INFORMATION: 1997, Beach Center on Families and Disability, 3111 Haworth, University of Kansas, Lawrence, KS 66045

This monograph, aimed primarily for families and educators, is the result of a study on friendship that focused on the Hispanic population. The intent was to find examples of "successful" friendships for children who experience significant disability. The stories are presented here, followed by a concluding section outlining "friendship tips" and giving additional resources.

TITLE: When Spider Webs Unite: Challenging Articles and Essays on Community, Diversity and Inclusion
AUTHOR: Asante, Shafik
PUBLICATION INFORMATION: 1997, Inclusion Press, 24 Thome Cresc., Toronto, Ontario, CANADA M6H 2

Shafik Asante was a leader in organizing to fight against injustices in the African American community, as well as in the struggle for better community services. He lectured internationally to diverse groups on community organizing. Topics addressed in this book include alliance building, inclusive community building, disability issues, and leadership and organizing, among others. The essays are based on reflections on the author's personal and work experiences.

TITLE: Building stronger communities for all: Thoughts about community participation for people with developmental disabilities
AUTHOR: Bogdan, Robert, & Taylor, Steven.J.
PUBLICATION INFORMATION:
In press, In A. Tymchuk, K.C. Lakin, & R. Luckasson (Eds.), The forgotten generation: The status and challenges of adults with mild cognitive limitations. Baltimore: Paul H.Brookes Publishing Co.

The authors question how can we think about having people with disabilities be a part of the community when community has become such a problem for everyone else, when community is under siege? They suggest that we must approach the challenge of helping people with disabilities to become part of the community with full appreciation of what is at stake. Thinking about community for people with developmental disabilities might help us think about it for ourselves. This essay presents some thoughts and observations on what it means for people with developmental disabilities to be part of the community.

TITLE: Involving All Neighbors: Building Inclusive Communities in Seattle
AUTHOR: Carlson, Carolyn
PUBLICATION INFORMATION: 2000, Seattle Department of Neighborhoods, 700 3rd Avenue, Arctic Building, Suite 400, Seattle, WA 98104-1848,
(206) 684-0464

This booklet was produced through the collaboration of the Seattle Department of Neighborhoods and the Washington State Division of Developmental Disabilities. It documents the "Involving All Neighbors" program, a program to promote neighborhood involvement by people with disabili-

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Resource Review: Promoting Friendships, Community Connections, and Membership

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ties. One unique aspect of this program is that it is located not within a disability agency, but within the City of Seattle's Department of Neighborhoods.

The booklet contains many different examples of people's involvement in neighborhoods, including individual connections as well as participation in neighborhood organizations and projects. The stories are accompanied by reflections on some of the lessons learned.

A conclusion offers some overall lessons learned from the "Involving All Neighbors" program, and the appendix contains the mission of the Department of Neighborhoods, and a summary of key aspects related to what makes neighborhood organizations inclusive, qualities of community connectors, and suggestions for ways that neighborhood organizations can include people with developmental disabilities.

Overall, this booklet contains many diverse examples of neighborhood involvement and reflections and lessons based on these experiences. As such, it offers creative ideas and strategies for all those who are interested in helping to promote community connections and meaningful community participation for people with developmental disabilities. Finally, it provides a wonderful example of partnership between community and disability focused organizations.

TITLE: Citizen Participation: Connecting People to Associational Life
AUTHOR: Gretz, Sharon
PUBLICATION INFORMATION: 1992, In Schwartz, David B., Crossing the River: Creating a Conceptual Revolution in Community & Disability. Cambridge, MA: Brookline Books.

This chapter describes some of the community-building efforts of a "citizen participation" project funded by the Pennsylvania Developmental Disabilities Planning Council. The chapter contains a number of stories about the creation of community connections. Embedded within these stories, as well as in some concluding remarks, are many lessons learned about the successes and challenges of community building, reflections on the ways that human service workers need to avoid imposing their "professionalism" on everyday community life, as well as reflections on the ways that engaging in community building challenges and potentially transforms human services.

TITLE: The Common Thread: A Collection of Writings about Friendships, Relationships, and Community Life
EDITORS: Gretz, Sharon, and Ploof, Dianna
PUBLICATION INFORMATION: 1999, Pennsylvania Developmental Disabilities Council, Room 559, Forum Building, Commonwealth Avenue,
Harrisburg, PA 17120

The stories in the monograph were originally published in a newsletter, "The Common Thread." The newsletter grew out of the work of the editors and others as part of the Community and Relationship Building Project at the UCP of Pittsburgh, a project funded through a grant from the Pennsylvania Developmental Disabilities Council. The purpose of the newsletter was to share stories about community connections and relationships and in doing so to stimulate readers to think more deeply about these aspects of human social life. In reflecting on the significance of the title of the newsletter and this monograph, the editors' write: "There are many things operating in today's society which work against a strong social fabric. Many of us feel deeply that when some people are excluded from the life of a community, the social fabric contains a hole. Perhaps each of our efforts can be considered to be weaving threads that have the potential to repair the hold and make some of our communities WHOLE—at least in some places and for some people."

TITLE: A Guide to Building Community Membership for Older Adults with Disabilities
AUTHORS: Harlan, Jane, Todd, Jennie, and Holtz, Peggy
PUBLICATION INFORMATION: 2001, Training Resource Network, Inc.,
P.O. Box 439, St. Augustine, FL 32085-0439

This publication is intended as a resource of ideas, tools, and techniques that have been found to be effective in helping to promote community membership for older adults with disabilities. Examples and stories are drawn from experiences of community builders and individuals with mental retardation and other disabilities who participated in a demonstration component of The Community Membership Project, a training initiative grant funded by the Administration on Developmental Disabilities and awarded to the Center for Aging Persons with Developmental Disabilities at the University Affiliated Program of Indiana. The stories are interwoven with information and interactive training activities, based on a community-building approach. The information in the guide is applicable to supporting people of all ages in community membership.

TITLE: Friends: A manual for connecting persons with disabilities and community members
AUTHOR: Human Services Research and Development Center
PUBLICATION INFORMATION: Human Services Research and Development Center, Minnesota Developmental Disabilities Council, 300 Centennial Office Building, 658 Cedar Street,
St. Paul, MN 55155

This manual grew out of the "Friends" project, a one-year grant project sponsored in 1989-90 by the Human Services Research and Development Center of St. Paul, Minnesota, and funded by the Minnesota Governor's Planning Council on Developmental Disabilities. The purpose of the project was to learn about and develop methods for the staff of residential service agencies to support people with disabilities in establishing friendships and relationships with nondisabled people in their communities and to assist people with disabilities in being more a part of their communities. Sections of the manual contain information on: planning with people; strategies to facilitate connections; introducing people; providing continuing support for relationships and friendships; assisting others in meeting and becoming friends with persons with disabilities; and agency support for relationship building. It describes the process used in the Friends project, strategies that seemed to be more and less effective, and it contains many stories and examples.

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Resource Review: Promoting Friendships, Community Connections, and Membership

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The manual would be useful for anyone who is interested in supporting a person with disabilities to widen his or her circle of relationships and to develop deeper friendships.

TITLE: "A feeling of being connected": Friendships between people with and without learning difficulties
AUTHOR: Lutfiyya, Zana.Marie
PUBLICATION INFORMATION: 1991, Disability, Handicap & Society, 6(3), 233-245

Recently, programmatic attempts to encourage close ties between people with learning difficulties and typical citizens have increased. It is believed that such relationships will extend the assimilation of people with learning difficulties into society. The researcher presents the perspectives of four pairs of friends about the meaning of their friendships. The informants shared similar ideas and expectations about the characteristics of friendship in general. These included its mutual, exclusive, and voluntary nature; the rights, obligations, and responsibilities of friends to each other; and the positive regard or affection found between friends. Despite efforts on the part of service providers to support the development of friendship between people with and without learning difficulties, the biggest barriers for the individuals in this study were the practices of the human service system, which curtailed opportunities for people which would have promoted the development and maintenance of friendships.

TITLE: Members of each other: Building community in company with people with developmental disabilities
AUTHORS: O'Brien, John, & Lyle O'Brien, Connie
PUBLICATION INFORMATION: 1996, Inclusion Press, 24 Thome Cresc., Toronto, ON M6H 2S5, Canada

This monograph addresses many issues and offers many stories and examples related to building community together with people with disabilities. The first chapter addresses issues related to community membership as a whole, including the consequences of social exclusion, the role of social support, and ways that human services can help. Following chapters address friendship, support circles, agency change, community building and supported living, signs of community building, and citizen advocacy. In a foreword to the book, Te Ripowai Higgins writes, "Members of Each Other...exposes the dangers of power, of isolation, of helplessness. It also challenges and gives hope for communities to take back control from the 'professionals', to themselves. This book gives tried and true tools to help build the future."

TITLE: Making friends: Developing relationships between people with disabilities and other members of the community
AUTHOR: G. Allan Roeher Institute
PUBLICATION INFORMATION: 1990

This book explores the issues of friendship and alienation. It looks at how the presence or lack of friends and other relationships affects individuals. It explores key elements of friendship, examines conditions that support the development of relationships, identifies key barriers that need to be overcome, and outlines practical options that can be pursued by those concerned with this issue.

TITLE: Social integration and friendship
AUTHORS: Strully, J. L., & Bartholomew-Lorimer, K.
PUBLICATION INFORMATION: 1988, In S. M. Pueschel (Ed.), The young person with Down Syndrome: Transition from adolescence to adulthood. Baltimore: Paul H. Brookes.

In the first part of this chapter, Strully and Bartholomew-Lorimer neatly summarize the experiences of many people with disabilities at the hands of the human service system. By receiving services, individuals are turned into clients and become viewed primarily in terms of their particular disability. They are surrounded by programs and staff, and are cut off from typical people, places and events. One result of this is that people in the community come to believe that segregation is an appropriate response to people with disabilities.

The authors propose that freely-given friendships between typical and disabled people "...are at the root of developing competent, caring communities for us all." They then present two case studies illustrating how to enable a person with disabilities to develop such friendships and the impact of these relationships for the people involved.

TITLE: From community presence to sense of place: Community experiences of adults with developmental disabilities
AUTHOR: Walker, P.
PUBLICATION INFORMATION: 1999, Journal of The Association for Persons with Severe Handicaps 24(1), 23-32

The places where people spend time and the experiences they have in these places are critical to the development of a sense of place and community connections. This study, based on individual experiences, reveals that adults with developmental disabilities commonly spend time in places designated for people with disabilities versus the general public, in public versus private places, and in places characterized by business transactions versus social interactions. Within the community, the research participants have a variety of experiences. They range from a sense of vulnerability to a sense of safety, a feeling of being socially anonymous or isolated to a feeling of being known, from disaffiliation to identification, from unfamiliarity to familiarity, from a sense of being rejected to a sense of being liked or accepted, and from a sense of unwillingness/willingness to provide accommodations. The article concludes with strategies that service providers and others can use to increase opportunities for positive community experiences and sense of place.

Preparation of this article was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred. The Center on Human Policy subcontracts with TASH for space in this newsletter.

TASH NEWSLETTER

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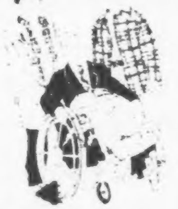
TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- Remembering Gunnar Dybwad
- In Memoriam: Stan Herr
- **Relationships, Love and Marriage for People with Developmental Disabilities**
- **Building Foundations for Friendships**
- **Personal Relationships Between People With and Without Disabilities**

Building Friendships and Community Connections



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TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

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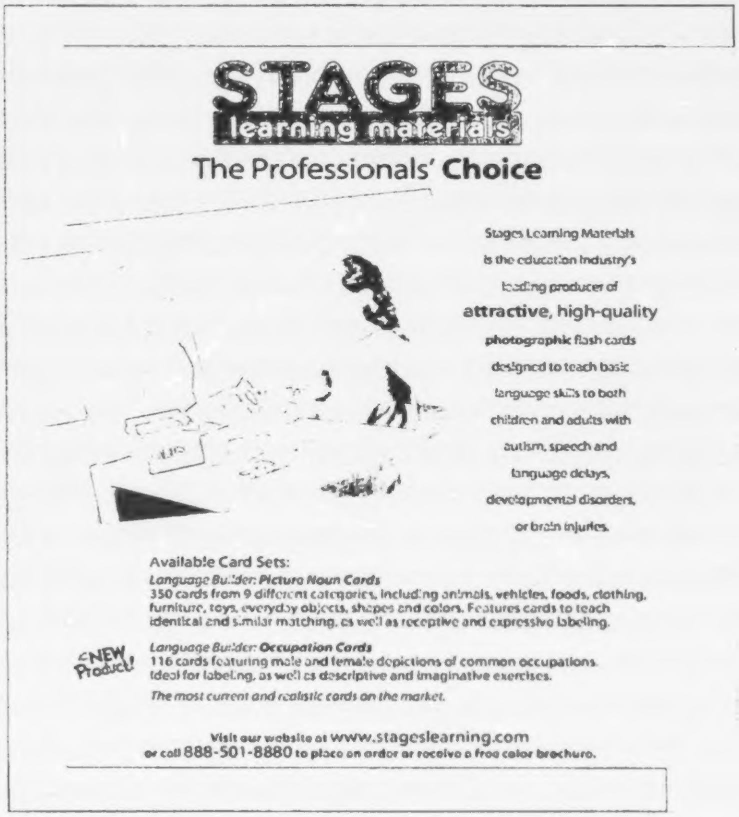

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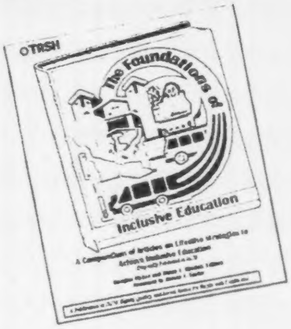

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Foreword by Steve Taylor

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From the Executive Director
BY NANCY WEISS

Together, We Can Triumph Over Tragedy

We have all indelibly been changed by the tragic events of September 11th. All of us, all Americans and citizens of the world, have had our sense of safety pulled out from under us. Some things that we thought we knew, we no longer know. Other things are even clearer than they were before. One thing that has been reinforced by these events is the importance of community. The events of September 11th have had impact on the disability community in many of the same ways that they affected people who do not have disabilities but there have also been some implications of these events that have been particular to the disability community.

Some of the ways in which the tragedies of September 11th have affected the disability community are obvious; others are less so. Most of the stories that have emerged from the tragedies have been horrific; some speak to the amazing spirit of mankind. There were people who survived the World Trade Center bombings who spoke of seeing people in wheelchairs waiting in the hallways while others rushed by them. As a society we have overlooked the survival needs of people with disabilities when elevators do not function. We have only begun to know how many survivors of the tragedies have survived with permanent disabilities. What we as TASH members have known all along is that when people are inherently connected within their communities, the quality of their life is enhanced. The events of September 11th have reminded us that not only do strong relationships result in better lives, they may well improve people's very chances of survival.

Many of us have heard the story of the man who used a wheelchair and was carried down sixty-eight flights of stairs by his co-workers. In 1993, when the World Trade Center was bombed the first time, John Abruzzo was among the last to get out. Back then, it took six hours for co-workers to carry him and his 150 pound power chair down 69 flights of stairs. In the aftermath of that event, Abruzzo's employer purchased a lightweight, sleigh-like evacuation wheelchair. On September 11th Abruzzo, and the co-workers who wouldn't think of abandoning him, made the same journey in a life-saving hour and a half.

With careful consideration and respect, the 2001 TASH Conference will be held as planned in November. While TASH knows that the recent tragic events have had a profound impact on all Americans and our neighbors worldwide, we believe that an event of this nature must serve as a uniting force for our community.

When the plane hit One World Trade Center almost everyone ran for the stairwell. John Abruzzo, a wheelchair user didn't run. Peter Bitwinski, a close friend and co-worker of Abruzzo's didn't run either. He began looking for the evacuation chair, described as a blue and yellow cradle on skis. He found it behind a stack of boxes. Eight other people held back and waited as others all around them ran for safety. Together they transferred Abruzzo to the evacuation chair.

Newsday reported, "Smoke already filled the stairwell when they started down. The smell of jet fuel choked them as they hoisted the chair down a few steps at a time. Carrying the chair was awkward and the men struggled to find a rhythm and synchronize their steps. They told jokes, their nervous laughter breaking the silence. Every few flights they would switch positions. They had to stop often to allow others to pass as workers rushed by to get out of the building". Bitwinski said later, "I just thought, we need to keep going down and get out. We had no idea the building would come down". Near the 20th floor a rumble shook the building and the lights in the stairwell went out. The other World Trade Tower had collapsed. Abruzzo, Bitwinski and their co-workers kept at it. They got out just moments before Tower One collapsed as well.[1]

This story is remarkable, as the events of September 11th were all remarkable, but the sense of community Abruzzo and his co-workers demonstrated is not remarkable in the disability community. We long ago realized the importance of community. Don Forrest, a member of Syracuse University's Center for Human Policy's Community Inclusion list serve said the following in a recent communication with that group:

"As I was getting dressed this morning, I saw my Center for Human Policy button with the inscription "Build Community" on it. What that has always meant to me is that I have a responsibility to get to know my neighbors and connect with them as part of our local community. I have done this in nearly every place I have lived, and it has always been a good investment of my time. It has made me feel safe, once I've gotten to know and trust my neighbors. It has made available to me resources that would have otherwise been unavailable. It has reinforced in me a real sense that no one can go it alone in this world, at least without the expectation of a somewhat depleted human experience of life. Knowing and caring about my neighbors has been, and

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Together, We Can Triumph Over Tragedy

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continues to be, a real gift both from me and to me in my daily life.

I know that most of us have spent quite some time thinking about ways to include folks with disabilities in our communities. We have even sloganized it: 'Build Community.' It seems to me that in these most difficult times, building community is just what the doctor ordered. Perhaps out of this tragic series of events, we may find that there is a real opportunity to put into practice, on a much broader scale, those beliefs that we hold in common. I'm hoping we work at that like never before. And I'm hoping that in so doing we can convert some of the fear and anger we are all now feeling into something that is really positive, and something that ultimately benefits everyone."

A few days after September 11th, I communicated with Bob Perske, one of TASH's most beloved members, and a national treasure in the tireless defense of the rights of people with disabilities. Bob and I talked about his early work in helping communities to be aware of the value of diversity. His book, New Life in the Neighborhood, was built on the following premise: not only is it good and important for people with disabilities to live in and amongst their non-disabled neighbors, it is good and important for everyone. Schools and neighborhoods grow stronger and prosper; not, as some might imagine, despite their differences, but instead, as a direct result of their diversity.

Bob said that one of his first glimpses of such healthy neighborly activity came from Dr. Paul Pruyser, a psychologist at the Menninger Foundation where Bob once worked. Bob said,

"Paul grew up in Holland, in a residential section in which all the houses were set back on their lots and separated by long, dense hedges. This allowed each homeowner great privacy. Then came the Nazi occupation and Paul became a heroic underground fighter.

Later, he told me something interesting about those hedges.[1] During the occupation, everybody cut openings in them, enabling people to move quickly and quietly from house to house — to share vital news and food and look out for one another. Also, members of the underground could flee through routes of hedge openings without being seen from Nazi patrolled streets. These cherished openings between the houses drew neighbors together."

Bob then told me a sad thing that Paul had shared with him. After the Nazis were defeated and Holland returned to being a safe and secure country, all of the hedges grew together again.

Bob drew the connection between the events of sixty years ago and the circumstances we face today. Bob said, "We are once again in an all-out war. Our lifestyles will be changed. Issues once receiving great emphasis will diminish. Other issues will rise up and take their places. Government funding streams will be redirected. I am old enough to remember our last all-out war and such wars are not kind to persons with disabilities." Bob suggested that the terrorist attacks of last month may be a national call to once again, "open up the hedges" that separate us from our neighbors.

Many people have asked whether TASH still is planning to hold our conference in Anaheim this November. TASH joins all of you, our fellow Americans and citizens around the world, in expressing outrage and sorrow over the events of Sept. 11th. Our thoughts, prayers, and support go out to each and every victim, survivor, and rescue worker, as well as their families and loved ones who have been impacted directly by the events of this truly tragic day; a day that will remain in our minds forever. TASH is built on determination and a commitment to strong communities. We have been touched by the world's outpouring of compassion around these tragic events.

This kind of uniting force is exactly the fortitude upon which TASH was built, and upon which our work together continues. Undoubtedly, our lives are forever changed. It is up to each of us to move forward, in support of each other, and to work toward emphasizing the value of life and the value of our interconnectedness as a community.

With careful consideration and respect, the 2001 TASH Conference will be held as planned in November. While TASH knows that the recent tragic events have had a profound impact on all Americans and our neighbors worldwide, we believe that an event of this nature must serve as a uniting force for our community. May we stand together in strength and decency, against all threats to our mutual safety and freedom.

In November, over 2000 TASH members and friends will gather in Anaheim to celebrate the accomplishments and the future of people with disabilities.

Join us in solidarity.

The following web sites provide information on disaster preparedness for people with disabilities:

http://www.redcross.org/services/disaster/beprepared/disability.pdf

http://www.ican.com/channels/independence/home/safety.cfm

http://www.ci.houston.tx.us/OEM/splneeds/

http://www.nod.org The National Organization on Disability's web site provides a number of valuable links for information disaster preparedness.

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[1] Newsday. September 22, 2001.

TASH: Public Policy In Action

TASH MEETS WITH ASSISTANT SECRETARY OF EDUCATION

Donna Gilles, Nancy Weiss and Jamie Ruppmann met with Dr. Robert (Bob) Pasternack the first week of October. The 90-minute meeting allowed time to cover several important topics with the newly-appointed Assistant Secretary of Special Education and Rehabilitative Services. Dr. Pasternack came to the U.S. Department of Education from New Mexico, where he was Director of Special Education. His past experience includes work with children who have deaf-blindness and youth with emotional disabilities. Dr. Pasternack has an older brother who has a developmental disability.

The meeting provided an opportunity to share the continuing concerns TASH has had about the preparation of teachers and other educational and support persons, particularly as it pertains to their ability to provide high quality instruction in community and inclusive classrooms and schools. Dr. Pasternack shares our passion for personnel preparation issues, and expressed some frustration with the continuing gap between research and practice. This gap exists despite the considerable dollars spent by federal and state governments, as well as local school districts.

The primary focus of the meeting was the use of restraints and aversive procedures in public schools. Dr. Pasternack agreed with TASH that information about incidence of abuse, injury or death need to be investigated and data collected that goes beyond the routine police or social services reviews that appear to be current practice in most communities. He pledged to collaborate with TASH to investigate this issue with an eye towards using the data to identify personnel preparation and school environment issues that may be contributing to the problem.

Dr. Pasternack has been invited to attend the 2001 TASH Conference in Anaheim next month. Barring unforeseen scheduling conflicts, he will address the full conference and then will be available for a "give and take" session on Saturday.

* * *

WHAT'S THE PROBLEM WITH "FULLY FUNDING" SPECIAL EDUCATION?

A majority of the members of Congress as well as a united educational establishment are calling for the "full funding" of special education this year. For TASH members and for parents and teachers across the country, the prospect of significant increases in federal dollars that "flow through" state departments of education to local school districts are something to welcome and support.

Senators Chuck Hagel and Tom Harkins introduced a "full funding" amendment to the Elementary and Secondary Education Act several months ago that has been the focus of petition drives and print ads in major newspapers (paid for by a coalition led by the National Education Association). One large suburban school district in Virginia even hired a lobbyist whose job is the passage of a full funding initiative. So what's the problem? Why aren't advocates urging passage of this amendment?

The answer is in the complicated formulas and funding requirements contained in Part B of the Individuals with Disabilities Education Act (IDEA). Currently, local school districts must use their "flow through" dollars to supplement the state and local money they receive to educate children in their communities. In this way, the federal funds contribute to the "excess" costs associated with providing the specially designed instruction and related services required to support students with disabilities who receive special education.

The Hagel-Harkin Amendment currently under consideration in the Congress would allow local school districts to use 55% of the new money as "local funds immediately." Further, where a local school district can "show that it is meeting the requirements of this part," [that is, Part B of the IDEA] then the local school district may "petition the state to waive, in whole or part, the 55% cap under this clause." Simply put, your local school district could be allowed to treat ALL the new funding as "local funds." It is likely that those "local funds" would be used for public schools. They might even be used to provide special education services. But, under this amendment there will be no requirement that the IDEA funds be used for special education. Many advocacy organizations, including TASH, can't support the notion that over the next ten years, local communities will receive vast sums of "special education funding" (close to $9 billion in 2002 up to a whopping $23 billion in 2011) that are not dedicated to special education services and supports.

It is also discouraging to realize that school lobbyists are characterizing this new funding as a "repayment" that they are entitled to because they have provided special education to youngsters with disabilities in their communities for the past twenty-five years.

It is true that over the years local school districts have contributed as much as 80% of the cost of special education, without much assistance from the state legislatures or the Federal government on a year-by-year basis. It may be reasonable for Congress to permit local school districts to take a portion of the increased funding for IDEA to supplement their general education funds. TASH, in coalition with several other grassroots advocacy organizations, met with Senators Harkins' and Hagel's staffs to talk over these concerns. We were frank in stating our belief that when families and advocates in the states realized what the true nature of the "full funding" legislation was to be, they would be shocked and angry. We have continued to monitor the deliberations of the Congressional Conference Committee working on the Elementary and Secondary Education Act and will post developments on the TASH web site as more information becomes available.

For questions about these or any other concerns about state and national policy, contact Jamie Ruppmann at jruppmann@tash.org or contact Jamie at the TASH central office at (410) 828-8274, ext. 104.

"Fully Funding" The IDEA? How About Fully Complying With the IDEA

BY REED MARTIN

For 26 years we have heard arguments about "fully funding" the IDEA. What does that mean? And where do the arguments come from? The arguments began when it dawned on school districts in the early '70s that Section 504 had been passed and school districts were going to have to provide an appropriate education to all students with disabilities. This meant that 1.25 million children with disabilities that schools had refused even to enroll, were going to be enrolled. It also meant that 1.75 million students with disabilities who were enrolled in school but, in the words of Chief Justice Rehnquist, "were left to fend for themselves in classrooms designed for their non-handicapped peers," were going to have to be provided an appropriate education.

This was a civil rights issue. The federal courts had decided 36 cases in 27 states that outlined what was required to meet the civil rights of students with disabilities. It was becoming clear that the civil rights of disabled students were right up there with black students, as recognized in Brown v. Board of Education, and with female students, as recognized in Title IX. These federal court cases, and Section 504, were based on the Fourteenth Amendment to the U.S. Constitution. When Congress recognized in 1990 — 17 years after Section 504 had been passed — that our nation's schools were still not meeting the Constitutional rights of students with disabilities, the Americans with Disabilities Act was passed. Section 504 did not provide any funds. Brown v. Board of Education did not provide any funds. Title IX did not provide any funds. The Fourteenth Amendment did not provide any funds. The Americans with Disabilities Act did not provide any funds. But schools have to comply with the Constitution and with those Acts.

Senator Trent Lott, introducing the current version of the IDEA for a final vote, May 14, 1997, reminded us: "The obligation to provide children with disabilities a free and appropriate education is grounded in the Fourteenth Amendment to the Constitution, Title V of the Rehabilitation Act (Section 504), the Americans with Disabilities Act, and by the laws of every State. IDEA is one additional civil rights tool that guarantees children with disabilities the right to receive a quality education."

So is the argument about "fully funding" the IDEA an argument that schools are only obligated to obey our civil rights laws if (1) funds are created to induce public schools to obey the law; and (2) the funds are adequate enough to interest the schools in coming into compliance with the laws? Schools must fully comply with Title IX, and Section 504 and the ADA, and the Constitution — with no federal funding.

When the IDEA was first put into debate in the Senate in 1975 (then called the Education for All Handicapped Children Act), there was an attempt to estimate the total cost of providing an education to the students with disabilities that schools had refused to enroll, and the costs of serving the students with disabilities that were enrolled but not appropriately served. The bill proposed that the federal government would fund a percent of that estimated total.

> **The argument for fully funding the federal effort is used by many school boards and districts to limit, not to expand, the opportunities for students with disabilities. They are telling parents, "your child's rights go only as far as the federal funding can be stretched to meet their needs."**

President Ford indicated that he would veto any new bill that came out of Congress with a call for increasing spending. So Senator Dole brokered a compromise that in the first years the federal share would be about ten percent and then, if the country could get past the ruinous inflation it was in, the Congress would consider raising the percentage of federal funding.

So what is "full" funding? Is it reaching the percentage of federal funding which was originally considered? That was far below 100%. So what is "full" funding? Is it reaching the original funding level in terms of dollars? That has been far, far exceeded already in terms of the billions that go into our public schools under the IDEA. Or is "full funding" a slogan that was created by school districts as an excuse not to comply with the rights of students with disabilities? This writer heard the argument over "full funding of the IDEA" again and again and again — from school boards, and teacher unions, and special education directors and administrators. We did not hear it from parents or from parent advocates. They were arguing for compliance with the law, no matter what the funding level.

But state education agencies and school district boards were using less than "full funding" to argue against compliance. The argument was put most succinctly to this writer by the state director of a major state — "the "feds" are only funding 10% so we will put only 10% into our effort to comply." That state director of special education testified to his state legislature that no additional funds were needed because their state was in total compliance with the requirements of the IDEA already. Then he would fly to Washington, D.C, on many trips, where he testified to Congress that the IDEA would bankrupt his state and that the

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"Fully Funding" The IDEA? How About Fully Complying With the IDEA

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federal government must put billions into his state before it could comply. When this writer published that testimony side by side in a newsletter it caused a bit of a stir. That kind of politically motivated lying characterized the initial arguments over "fully funding the IDEA." And the arguments came exclusively from the administrative side.

Now, the coalition includes parents and we still wonder what "full funding" means and what obligations schools are recognized to have until "full funding" is achieved. The reason parents are talked into joining such a coalition is that school personnel keep lying to them — "we could do what your child needs if only we had more money." Then the school personnel divert the parent advocacy efforts away from compliance and into fund raising for the school. We saw a newspaper article last year in which a student was failing badly in school for lack of a piece of assistive technology that any honest IEP would have included. The school convinced the parent to do extensive private fund raising in the community to purchase the equipment. When that was successfully done, the parent gratefully thanked everyone because her child could now have a chance at an appropriate education. The school never accepted the responsibility for getting this equipment.

There has been a massive amount of funding up to now, since 1977. Your state education agency and your local education agency have pledged, in sworn affidavits sent to the federal government, that they are in full compliance with the law, and that they are therefore eligible to receive the federal funding. If they are in full compliance now, why the need for any increase in funding? Are they lying about being in full compliance? The federal government backed off of monitoring the states closely in the past decade because their monitoring showed such waste and misuse of funds being received. In one state, this writer asked for information about the amount of IDEA funds that were "misused" the previous year and thus ordered to be returned to the treasury. The answer was in the millions. This writer then asked for the amount that had not been obligated during the fiscal year, and thus would have to be returned. (These funds are not actually returned; they are deducted from the next year's amount). That non-obligated amount was also in the millions for that year. So with funding at that level, we had millions in misuse and millions not used. We wonder what "full funding" would bring.

The key is not "fully funding" -- whatever that means and whatever the amount is. The key is the recognition that these students are not "special education students." These students are our students, and they have special needs. They have a right to local funds and a right to state funds to meet those special needs.

The funding under the IDEA was also recognized from the beginning as being required to "supplement" state and local funds, not "supplant" them. In other words, the federal dollars were to add to the state and local effort to meet the needs of students with disabilities. Yet, monitoring reports have consistently shown that schools use local dollars for purposes that they prefer (for example astro-turfing the high school football field), often limiting the funding of special education needs to the available federal special education dollars. That is a clear violation of the law and a clear violation of the rights of students with special needs, but it can be traced to the attitudes of some school personnel that "federal funds have to fund the federal special education requirements and we will only go as far as the federal funds go."

In other words, the argument for fully funding the federal effort is used by many school boards and districts to limit, not to expand, the opportunities for students with special needs. They are telling parents "your child's rights go only as far as the federal funding can be stretched to meet their needs."

The federal laws require the opposite. These children with special needs are our children. They have rights equal to any other student in the entire school district. They are not federal students, to be put into federal programs, and to be funded to the limit of the federal contribution. Our children have an equal claim on every dollar — whether federal, state or local — that is available to every other student.

The notion that "full funding" is what is required before a school district "fully complies" is what leads school personnel to say "we are out of federal evaluation dollars for this year;" "we don't have enough federal funds for a program in your neighborhood school, so you will have to go across town to the one we pay for with federal dollars;" "we only have enough federal funds for one bus, so all the students in that building will have to leave earlier than the other students;" "we do not have enough federal funds to afford an aide for that one student;" "we don't have enough federal dollars left in the budget to afford a piece of assistive technology that would allow that student to be in regular classes;" and "we cannot allow an aide to help your child toilet herself until we get clearance to use federal funds for it." The last example was one this writer took all the way to the U.S. Supreme Court and won 9-0, with the school district paying their attorney $562,000 to fight this. Is that a problem caused by "lack of funding" or a problem of a lack of commitment to our children?

The Americans with Disabilities Act, Title III, applies to private schools. (Title III of the ADA requires places of public accommodation, like schools, to

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"Fully Funding" The IDEA? How About Fully Complying With the IDEA

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be accessible to people with disabilities.) No federal dollars are involved, but full compliance is required. Is there a call to "fully fund" Title III? No, but there is a call to fully comply with Title III and this writer has certainly litigated under Title III, expecting full compliance. We have had increases in federal funding for the IDEA year after year after year. Does anyone feel that has helped us reach greater compliance? No. In fact, the National Council on Disability report issued last year suggested that at the time of the highest funding of the IDEA, noncompliance with the IDEA was rampant.

The key is not "full funding" — whatever that means and whatever the amount is. The key is the recognition that these students are not "special education students." These students are our students and they have special needs. They have a right to local funds and a right to state funds to meet those special needs.

They should not have to wait until their school district and their state are satisfied with the amount of federal dollars they are receiving before their state and local school district begin to comply with 30 years of laws. We should expect that their state and local districts will start complying with the sworn statement that they have been sending annually to Washington D.C. for the past 25 years — the sworn statement that they fully comply with the federal laws.

We are for "fully complying" with the federal laws and not for giving school districts some "lack of funding" excuse for treating our children as less than full citizens until the school can draw down enough federal dollars to make our children worth their while.

Reed Martin is a friend to our children and an attorney with 33 years experience in special education law. He can be reached by e-mail at connie@westco.net or visit his website at http://www.reedmartin.com

Don't Forget

The deadline to pre-register for the TASH Conference in Anaheim is November 5th!

All registration forms must be received in Baltimore (by fax, mail or electronically) by November 5th in order to be processed as a pre-registration.

There is no problem registering on-site, but after November 5th, registration will be on-site only and an on-site fee of $25 or $50 will be added.

Academic Inclusive Momentum

Texas Middle School Inclusive Education Grant Project implemented by LR Consulting and funded by Texas Council for Developmental Disabilities

Wanted:

Lessons that enable students with developmental disabilities to access middle school general education curriculum. See web site for details.

Bookmark this site and visit it often for project updates:

www.inclusivemomentum.com

For Whom The Bell Tolls: Relationships, Love and Marriage for People with Developmental Disabilities

BY DAVE HINGSBURGER

“My mother told me I shouldn't have kids because they'd come out like me. Is that true?” The speaker, a charming young woman with a developmental disability, is desperate for information. I had met her during a project aimed at raising public awareness of the value of the work that people with disabilities do in their communities. Ironically, this young woman works as a nanny for two young boys. During the day she takes care of another woman's children. She and her boyfriend desperately want children but are being counseled on all sides to abstain from sex thereby avoiding pregnancy. There are tears in her eyes.

The source of those tears could be threefold. First, she might simply be frustrated at her inability to find someone, anyone, to answer her questions. Second, she might be grieving a child that she wants but believes that she should not have. Third, she might be coming to the realization that many people believe “being like her” is such a bad thing that it should never happen again.

That people are uncomfortable with talking about sex is nothing new. That people are uncomfortable with disability is something not spoken about. It is not surprising then that sexuality and disability together can be a toxic mix. For people with disabilities to develop into healthy sexual beings they must navigate a minefield of myths, misconceptions and outright lies. Further, they need to develop a strong sense of self and personal worth to withstand the onslaught of negative messages that exist in the community regarding both sexuality (you have to be beautiful to be loved) and disability (you are unworthy, unattractive and unlovable). Finally, they need to have developed enough assertiveness skills to demand accurate information and to stand up to disapproving others.

Yet, the mere fact that this woman is in a relationship, and that she loves a man who loves her back, is a testament to the fact that the world is changing for people with disabilities. While she lives in fear, she also lives in love. She's half way home. As more and more people with disabilities seek out partners, we need to conceptualize how to help a person with a disability achieve healthy sexuality. Accurate information, self esteem and assertiveness, are the ways that all people grow into sexually competent individuals, so it isn't a stretch to suggest that the same is true for people with disabilities.

Accurate Information

Years ago a young researcher attempted to develop a Sexual Knowledge Test for people with disabilities. He approached the sexuality clinic at York Central Hospital. The clinic had been serving people with disabilities for several years. It was his goal to run his proposed test with several people with disabilities, and he wanted to use their care providers as a control group. The test was only on sexuality - there was no information specific to disability.

As he ran the test, he kept revising it and making it more simple. His process of simplifying the test wasn't because of the responses of people with disabilities. Rather, he was having difficulty making a test that the care providers could pass!

There is an assumption that those without disabilities have all had adequate sex education, are perfectly comfortable with their bodies, and have healthy attitudes towards masturbation and menstruation. In a word, wrong! This situation could be amusing, if it wasn't for the fact that people with disabilities often seek information from their care providers. Without meaning or malice it may be that the care provider may simply pass along either personal values or societal myths rather than information. “When I want to have sex with my girlfriend, am I supposed to wear a condom even if she is on the pill?” is a legitimate question. “You shouldn't wear a condom because you shouldn't have sex until you are married,” isn't a legitimate answer.

Care providers need to have access to resources that will help them answer questions. Further, they need to learn professional boundaries. Asking someone for information is different than asking for his/her opinion. It is imperative that care providers learn the difference between the two. A further complication is that many people forget that “values” are “opinions,” and instead mistake “values” for “facts.”

The statement, “Homosexuals are deviants,” believe it or not, is a value, not a fact. No matter how strongly one believes something, it doesn't make it a

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For Whom The Bell Tolls: Relationships, Love and Marriage for People with Developmental Disabilities

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fact. Training care providers to access good information and to put boundaries around their own belief structures may be some of the most important training done for those in service to people with disabilities. The same, however, is true for parents. Parents need to learn that their child is an individual, separate from them and as such, need to be able to make independent decisions. Typical children will accept, or reject, your belief structure -- and you have no choice but to cope with their decision. It can be tempting to ensure that a child who is more vulnerable to your control will follow completely the rules you set for them. Tempting though it may be, it is a temptation that must be resisted.

Accessing information, though, is no longer particularly difficult. Informative, well-written books on sexuality exist for those seeking general information. However, when there is an identifiable disability present, like Down syndrome or Prader Willi Syndrome, there is often information specific to that disability (the fertility of men with Down syndrome, for example) that you will need to access to fully answer questions. Further, if there is a physical limitation such as often accompanies cerebral palsy, there may be questions like, "how can I masturbate when I have difficulty using my hands?" Fortunately, anyone with access to the Internet can find resources that will provide pertinent information. SIECUS (Sexual Information and Education Council of the United States), for example, has perhaps the best resource list on the Internet for information related to sexuality and a variety of disabilities.

> **People with disabilities who want to form relationships and who live within systems or families that disallow them from becoming full adults, need to find their own voice and to use it.**

Self Esteem as a Person With a Disability

People with developmental disabilities understand negative messages, no matter how subtly they are transmitted. The woman who asked the question about the possibility that her child may have a disability was keenly aware about the fear that others had of her child's possible disability. She made the easy "connect-the-dots" link between "we don't want your child to have a disability," "we don't value people with disabilities," and "we don't value you." Interestingly, in talking with her for only a few minutes, she was more relieved to get a message that it was okay to be her, than to learn that her child wasn't likely to have a disability.

Others learn, through practice, that they shouldn't associate or have friends with disabilities. As laudable as this idea might have been for bringing integration into the lives of many people with disabilities, it is an idea that has a dark side. A person with a disability who first learns that they shouldn't associate with "someone like that," and then learn that they are "like that" can be traumatized emotionally and socially. Self-loathing can lead to all sorts of behavior wherein people with disabilities become vulnerable. Recently at a parent workshop, I asked the parents to raise their hands if they felt that their children could be lured into unwanted sexual practices by a manipulative person who used praise as the "candy" reward. Almost all parents raised their hands. Then followed a discussion about how their teenaged children would do anything for social approval at school.

The hateful movie, "Something About Mary," presented exactly this scenario at its beginning when a young man with a developmental disability is tricked into doing something seriously wrong by young men who offered only approval and faint friendship overtures. Self advocacy may be the only way out of this quagmire.

The self advocacy movement allows people with disabilities not only opportunities to meet others who have disabilities, but also to confront any internalized self-hatred of disability. Like consciousness raising groups formed by feminists in the sixties, self advocacy groups that become disability aware and disability proud offer stunning hope for the disability community. A couple with a developmental disability in New York City became the first people with this kind of disability in the world to adopt a child. They attribute part of their success and determination to the self advocacy movement and to their understanding of themselves as citizens with rights. The self advocate movement has a long way to go, but its promise is boundless.

Astra Milberg, a woman with Down syndrome, in her famous "Letter to a baby who was thrown from a bridge," advises young people with disabilities to feel proud, to find places where they belong, to join self advocacy movements, to expect a life full of love and relationships. Her stunning statement of self-worth, "God gave me an extra chromosome, it's an odd gift but it is a gift" is an example of what pride can do in the life of a person with a disability.

Assertiveness Skills

People with disabilities who want to form relationships and who live within systems or families who disallow them from becoming full adults, need to find their own voice and to use it. They need to be able to speak clearly for what they want and to stand up to the powers that be. Often advocates for people with disabilities make the mistake of advocating for a person with a disability who wishes to form a relationship. The mere fact that someone else is doing the advocating communicates a lack of competence in the individual being advocated for.

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For Whom The Bell Tolls: Relationships, Love and Marriage for People with Developmental Disabilities

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The individual must speak to the issue him or her self.

With one individual who asked me to advocate for him, I told him that if he couldn't stand up to his mom and tell her what he wanted, then maybe he wasn't ready for the right to a relationship. We role played a number of ways of approaching the issue. When I went with him to speak to his family, he threw out all of our training and said instead, "Mom, do you know that I love you?" His mother said, "Of course I know you love me." Then he looked at her and said directly, "Then why do you think I shouldn't be able to love someone else? Is it because you think I won't have enough left for you?" That simple beginning began a profound turnaround in his relationship with his mother. He is married now and his mother proudly supports him in his relationship. This wouldn't have been possible unless he did the work himself.

One of the tenants of feminist psychology is that therapists should never do work for the individual that belongs to them. This simple approach needs to be adopted by care providers and advocates in order for people with disabilities to learn to stand their ground and to fight their own battles. This is what adults do.

Most of us are endowed with the capacity to love

Sexuality and disability shouldn't be controversial. It only becomes controversial when negative attitudes toward one or the other overwhelms the positive benefits of both. Married men and women with developmental disabilities are a testament to the capacity of all to love, to bond, and to form relationships. Next time the bell tolls for a person with a disability there is a better and better chance it will be a wedding bell.

Dave Hingsburger is a world-renowned author, speaker, and behavior specialist. He is in private practice and is a consultant to the Sexuality Clinic at York Behaviour Management Services in Richmond Hill, Ontario, Canada.

For a list of titles authored or co-authored by Mr. Hingsburger, please visit Diverse City Press's web site at www.diverse-city.com, where you can also obtain ordering information for Astra Milford s book, "Letter to a Baby Thrown from a Bridge."

Where Science, Advocacy and Values Meet

Have you used research in furthering your advocacy work?

Have advocacy agendas influenced your research?

We are working on a special issue of TASH *Connections* that looks at ways in which research and advocacy can work together to promote social change. We want to hear your thoughts and experiences. If you have found ways to build collaborative partnerships between research and advocacy agendas, or if you have experienced situations in which research and advocacy have been at odds with one another, we want to hear from you. Please send your experiences to Nancy Weiss at nweiss@tash.org or mail your article or brief discussion to Nancy at: TASH, 29 W. Susquehanna Ave., Suite 210, Baltimore, MD 21204.

DOCTORAL STUDY IN SPECIAL EDUCATION AT

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Program Coordinator
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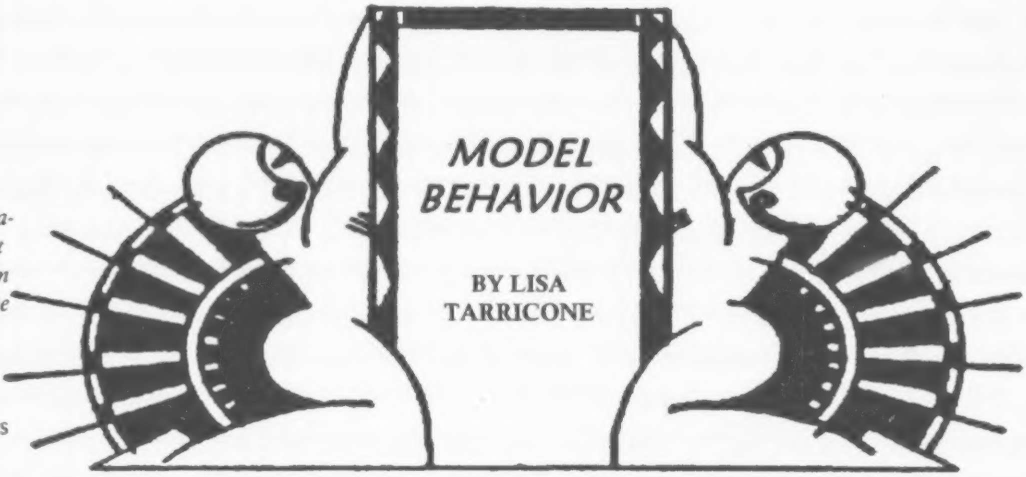
Contact with individual program faculty is welcome.



MODEL BEHAVIOR

BY LISA TARRICONE

There's nothing as unimaginative as popular culture when it comes to sex. If any group can break that stranglehold, it's the disability community.

It's difficult for some of us to stare back at an airbrushed image of physical perfection, say in Playboy or muscle magazines, and not start contemplating deeper issues of self-worth. We keep telling ourselves that the quality of our lives and our attractiveness should have nothing to do with flawless skin and bodily virtue -- but they seem to anyway.

In the realm of disability, these issues are even more intensely felt. They go right to the heart of sexual self-esteem for those of us struggling to maintain visibility within a culture that imposes ruthless standards for attractiveness and desirability. The mandate, or so it would seem for individuals with disabilities, requires a sort of physical legitimacy in order to obtain love and acceptance, with a certain sexual model as the gateway to both.

We are overwhelmed with television, magazine, and billboard ads using conventionally beautiful bodies to sell everything from jeans to taco chips. Sexual value has a certain cultural look that typically does not include people with disabilities. When was the last time you saw an attractive woman in a wheelchair selling Slim-Fast, or a Paralympic athlete posing for a Gap ad?

As popular culture continues to promoteand blithely accept images that connect sexuality to body perfection and beauty, the polarization between those who have the ability to meet those standards and those who are unable to will deepen. In his 1998 book Nothing About Us Without Us, James Charlton outlines several reasons why this trend is likely to continue: "The implication of the present image of the disabled body...leads inevitably to the notion that people with disabilities are asexual."

Charlton claims that this is a compelling myth among non-disabled people due not only to the cultural fixation on body imagery, but to the "medicalization" of disability, as well. Disability is frequently linked with illness and dependency, and this often has an oppressive effect upon those who are struggling for sexual equity. There is so little, and at times, inaccurate, information available regarding the sexual potential of people with disabilities or the non-standard forms of sexuality that frequently come up in the community. This is yet another area in which people with disabilities have a lot to teach those without disabilities who define sexuality so narrowly.

"Just Say No," They Tell Us

Jamie, a young woman in her late twenties from Port Chester, New York, is an outpatient at a local rehabilitation facility due to paraplegia from a recent spinal cord injury. "My orthopedist told me what to expect after my injury," she recalls. "He basically told me to concentrate on my upper body and ignore the 'wasted muscles' in my legs." When Jamie asked her physical therapist whether or not she would be able to have a sex life again, she was informed that it would probably never be satisfying and that she would have to find someone very "special" to understand her "condition".

With comments like this from supposed experts, it's no wonder that individuals with disabilities often begin to confuse rigorously defined standards of acceptable body dimension, weight, and physical competence with the ability to be sexual. This becomes a discouraging and unrelenting process for those who don't measure up to the standard norms for physical acceptance.

Jamie confessed to feelings of shame and fear when confronted with the possibility of sexual intimacy due to negative

Disabled author Gary Karp and other advocates agree that everyone has the potential to be a sensual being, regardless of any physical disability, and it is up to that individual to either choose to resist or affirm certain popular conceptions that attempt to stigmatize disability as undesirable.

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MODEL BEHAVIOR

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stereotypes that she internalized regarding her body. "It feels like I am not entitled to have sexual feelings anymore," she admits. "Not only do I feel unattractive, but it almost seems like my body has lost the capability to respond to sexual cues."

The revised edition of the famous Kinsey Report, released in 1998, confirms this crucial link between body image and sexual self-esteem: "A positive body image is an important part of self-esteem, and having high self-esteem is vital to establishing intimacy with others. It is the belief that one is valuable and deserving of loving relationships." The same report cited the importance of "being secure enough to risk having a lover find out that you are not completely perfect."

The salvageable message in this for people with disabilities at odds with the misguided cultural connection of disability and sexlessness is in the notion of "security." "Intimacy has really less to do with sexual 'function' than many people assume," says Gary Karp, an author who has a disability. He argues that the more intimate levels of sexuality are driven by deep emotions, that it is "sincere loving contact," which ultimately heightens security. Plus, he adds, "Stronger feelings make for better sex."

Still Seriously Sexual

Karp and other advocates agree that everyone has the potential to be a sensual being regardless of any physical disability, and it is up to that individual to either choose to resist or affirm certain popular conceptions that attempt to stigmatize disability as undesirable.

Consider Ellen Stohl, a person with quadriplegia, who posed on the cover of New Mobility magazine a few years back under the heading "Still Seriously Sexual." In that one cover shot, Stohl, her long legs clad in black fishnet stockings, straddled her wheelchair with a self-possessed posture that flies in the face of negative stereotypes linking sexuality and disability. "I'm a woman; I happen to be using a wheelchair, but I'm a woman first and foremost," she told a television interviewer in 1987.

And what about men? Do they consider themselves men "first and foremost" in the same way? "It depends," says Burt, a gay male who sustained a cervical spinal cord injury over 10 years ago. "I now look at different aspects of sexuality—I'm not solely fixated on my ability to have an erection." He maintains that his sexuality entails more of an erotic exploration into massage, passionate kissing, and various forms of touch. "There is still a way to fuel your passion and connect as a sexual and sensual human being," says Burt. He says he encounters his share of rejection; however, he points out that finding romantic partners is not as difficult as he once thought it would be. "There are so many people out there searching for a connection," he says. Disability or not, this is of course what it's all about.

Reprinted with permission of WeMedia. About the author: Lisa Tarricone is a writer who lives in White Plains, New York. She is assistant director of Alive To Thrive, an organization that provides diversity and sensitivity training for corporations about people with disabilities. Comments about this article may be addressed to Ms. Tarricone via e-mail, <ltarric664@aol.com.

Rosemary F. Dybwad Fellowship

Rosemary F. Dybwad International Fellowship Trust, Inc. provides fellowships for international travel and study projects. The projects funded involve a stated purpose to further the understanding between and among nations and in the past have ranged from comparative studies, research, and experiential learning to program analysis.

Inspired by the lessons to be gained by international experiences, previous awardees have brought their lessons learned back to their own countries and their writings, lectures, speeches, and publications have had a far-reaching impact which has shaped the field of intellectual disabilities.

The Trust is currently seeking applications for projects to be funded in 2002. Individuals submitting project applications should:

a) have a demonstrated track record and interest in the field
b) be able to leverage additional resources in support of their work
c) have clearly identified avenues and strategies for dissemination of the Fellowship results
d) produce high quality written reports of their experiences and study
e) demonstrate to the Trustees a plan for achieving a broad impact from the Fellowship

Applications must address: title of the proposed travel/study project, country(ies) to be visited, travel dates, what is intended to be accomplished, method to be followed to conduct the project, primary contacts in the host country(ies), dissemination plan for the projects results, accompanying person in travel/study project, and the amount of funds requested. The Trusts International Fellowship Application must be used in the submission.

Currently, Fellowships are being given out in amounts of no more that US$4,000. Applications are open to anyone interested in obtaining support for an international travel project. The Trust currently has an open application period, but applications submitted by December 1, 2001 will receive priority consideration for funding in 2002.

For more information and the International Fellowship Application Packet, contact:

Dr. Constance Kane, President
Rosemary F. Dybwad International Fellowship Trust, Inc., 90 Carlton Street, Brookline, MA 02446 USA; Telephone: (617) 730-4365; Fax: (617) 730-5616; Email dybwadtrust@aol.com

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TASH's work is dependent on the financial support of our members and donors. We wish to acknowledge the generous assistance of the following individuals:

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CELEBRATING THE LIFE AND LEGACY OF GUNNAR DYBWAD

Remembering a True Civil Rights Champion

I learned of the death of Gunnar Dybwad, as so many of us did, in an e-mail. It is remarkable to think that a man who was born in 1909, when speed was measured in a few miles per hour, had his death notice and eulogies ricocheted across the globe at the speed of light.

In the first hours and days following the announcement of his death many of us attempted to put our sorrow into writing. What follows is a collection of e-mails reflecting on Gunnar, his life and his death. Some of them came to me, some went to the family, and others were posted on listserves as we all struggled with the news.

Befitting the scholar who was the subject of the messages, the first notice which was replied to over and over was titled: The last chapter. We all knew immediately that we had lost him.

Friends, former students and distant admirers all had memories to share. I have collected several hundred reflections and, with the Editor of TASH *Connections*, I have selected a few to share with you here. Only minimal editing has been done to preserve the immediacy of the comments and the intensely personal reflections being shared by so many of us.

Hank Bersani

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I was already numb by the tragic news on Tuesday [September 11] and now I hear of Gunnar's passing -- a day we all feared would come too soon. It is comforting to know that Gunnar's circle of friends and family were with him throughout this last ordeal. Yesterday, Gunnar was characteristically himself -- complaining to Martha when she tried to clean up after his dinner (his appetite never waned during his hospitalization). Bill provided humor and comfort to Gunnar these last days and calmly listened to Gunnar's complaints about the lateness of breakfast, etc. This man who fought incessantly for the dignity and rights of people with disabilities -- died with dignity, surrounded in cyberspace by caring messages from those who were touched by his life and his vision for the future for people with mental retardation.

Barry Schwartz

◆ ◆ ◆

I am writing to say that we have had a great loss today, in the self-advocacy movement and also in the disability field. Gunnar Dybwad died at 12:30 this morning.

He was one of the first professionals who really believed in what SABE [Self Advocates Becoming Empowered] stands for. He was 92 years old, and he was a very wise person who always spoke his mind. He always supported the self-advocacy movement and helped people believe in themselves. He really heard what self-advocates are saying that they want in life, and he challenged the service system to really respect what self-advocates were saying. He challenged them to value us and to look hard at how they were developing services for us. He was one of the first to say that people should move out of institutions and other kinds of congregate living. He was one of the firm believers in what we call "community" now, but before any of the services we have now were in place in the community.

We have a "little Gunnar" inside of each of us, no matter whether we are a self-advocate or an advisor. At the next SABE board meeting, I want to have a small memorial service for Gunnar. Those who knew Gunnar can tell those who didn't know him who he was and why we are where we are today. I just want to add that I want to keep Gunnar's dream and vision alive in the self-advocacy movement and in the disability field.

James R. Meadours, Chair
Self Advocates Becoming Empowered

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Marsha Forest, Gunnar and Jack Pearpoint at the 1997 TASH Conference in Boston.

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CELEBRATING THE LIFE AND LEGACY OF GUNNAR DYBWAD

Continued from page 16

I had the privilege of spending a few days with Gunnar at his home a few years back, recording a small bit of his knowledge on video for a history project. We recorded his interviews at the Samuel Gridley Howe Library, of which he was extremely proud. Apparently a few people were bothered by the fact that he was establishing his library on the grounds of an institution. His response: "You don't go to a beauty school to study auto mechanics."

Jerry Smith
ACT

◆ ◆ ◆

As all of you know, Gunnar was a staunch supporter of the self-advocacy movement. When People First of Tennessee filed a lawsuit against Arlington Developmental Center, he offered to do whatever he could to help. Our biggest battleground in that case was People First's motion for class certification.

The Parent-Guardian Association of Arlington Developmental Center had intervened to oppose class certification and filed almost 140 declarations of parents opposing representation of their sons, daughters and wards by People First. The judge was sympathetic to the parents and wary, if not hostile, to People First. Gunnar agreed to testify (and as always, he refused any payment for his work).

With authority and dignity, Gunnar vouched for us. After the hearing, the judge certified the class, in one of the best decisions on class certification that has ever been issued in an institutional case. People First went on to win consent decrees in Arlington and in a subsequent case, People First of Tennessee v. Clover Bottom Developmental Center, under whose terms every institutional resident in the state is now slated for community placement. I'm sure it never would have happened without Gunnar.

Judith Gran
Public Interest Law Center of Philadelphia

◆ ◆ ◆

Doug Biklen and Gunnar

Dear Families and Friends of Gunnar Dybwad:

We join you in celebrating one of the greatest lives ever lived. Gunnar Dybwad made profound contributions to the culture of human being.

The monuments to his being — self-multiplying increases in the quality of human life — will exist long after the pyramids of Pharaoh have crumbled to dust.

We are so fortunate to have had Gunnar as one of our mentors. We are so proud to have been associated with him -- and with you — in the struggle for a just society.

Now all of us must rededicate ourselves to passionate advocacy for the principles which Gunnar symbolized.

As always, we will be with you in passion and spirit. We love you. Lead on.

Justin and Yoshiko Dart

◆ ◆ ◆

I will always remember Gunnar's sense of humor. He was the master of the set up, only to clobber you a moment later. After one of his hospitalizations, I was spending a few days with Gunnar -- cooking, and helping with some writing. One night I cooked some very nice fresh vegetables, and felt like it was a rather nice dish. Gunnar said "You could cook at any of the finest restaurants in Boston." I was quite self-satisfied that "The Old Professor" approved of my cooking. Then it came. "Yes! They never cook their vegetables enough either!!!"

Another time he and I were speaking together. I have lost track of the time, the place and the subject. In the opening comments, I was talking about the idea of a "paradigm shift," an idea I was quite fascinated by at the time. In just a few minutes, I managed to say "paradigm shift" about 5 or 6 times. Finally, Gunnar drew himself up in his seat, grabbed the microphone and announced, "Are you sure there is an 'f' in that shift?"

Hank Bersani

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What I think Gunnar was trying to say to you [Hank] is, "Go get me a Big Mac or a Whopper." That you would go spend some time with Gunnar after one of his hospitalizations is an act of goodness, kindness, and respect—and I'm sure that Gunnar knew this, despite your vegetarian persuasion. We need more acts of goodness, kindness, and respect in this world—not fewer.

I am wondering what Burt [Blatt] or Gunnar might be saying about the sorry state of human affairs right now. Burt would quote the scriptures and give us a moral compass, though not a map. Gunnar would be his optimistic self. He would remind us that the forces against slavery won the Civil War, that Nazism was beaten back, that the people of America rose up against and demanded an

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CELEBRATING THE LIFE AND LEGACY OF GUNNAR DYBWAD

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* * *

end to the Viet Nam War, that the Jews on this earth deserve respect and a special place in world history for their suffering, and that we have defeated the worst abuses committed against people with disabilities in American society. Whatever injustice or threat you brought to his attention, Gunnar would be confident that we could defeat it.

These are just conversations I contemplate having with Burt or Gunnar. I cannot speak for either of them, obviously. I can only write about what I learned from them.

Steve Taylor
The Center on Human Policy

* * *

Gunnar's very first words to me were on the telephone, in response to a question that I asked him in 1972 about ways to improve Belchertown State School. "Blow it up, darling," he told me, "that's the best thing that you can do."

I had been advised to call "Professor Dybwad" who was reported to have information and opinions about Belchertown to get some advice. I don't remember much about the assignment, but the call to Gunnar was the beginning of an enduring friendship, mentorship, and education about human-centered design of places.

Gunnar was an extraordinary influence in my life. I treasured his phone calls that often gave me challenges, and miss being able to call him to ask for advice or to report an outrage or a success. I touch his papers with love, am grateful for him, and miss him very much.

Elaine Ostroff, Founding Director
Adaptive Environments Center

* * *

The lengthy international struggle to achieve full lives with and for people with intellectual impairment has lost its most consistent, energetic, inspiring and ubiquitous champion.

I first met Gunnar (and also Rosemary Dybwad) a quarter of a century ago in London as we were building a coalition to shape a new vision of "An Ordinary Life" for people with intellectual disabilities and their families. It is a measure of Gunnar's consistency and ubiquity that whenever we have met since -- for example, in recent years in Prague, Helsinki and Vancouver -- he insisted we go for "English tea" so he could catch up with our efforts and offer further inspiration. As in many countries, he had so many friends here that about once each year until very recently, around the time of his birthday, a small crowd of us would meet up for Sunday "brunch" in Hampstead to eat and drink of course, but also to renew our sense of purpose in the light of Gunnar's unique world view.

Indeed, it is a measure of his commitment that even birthday parties were not allowed to pass without a serious reminder to us of how much more there is to do in this struggle. More publicly Gunnar was also brave in reminding us continually about the extent to which professionals working in this field had historically failed people with intellectual disabilities (no one remembered this history better than him); and equally, seeking to document and reinforce the steady growth of the self-advocacy movement as a key force for positive change.

We have lost a great champion: but we keep a great inspiration. We now all have more to do to deliver on the vision.

David Towell
King's College, London

* * *

I didn't think things could get any worse this week and now they have.

Ronnie Cohn

* * *

Is it a coincidence that one of the last humanitarians of the world, a man of wisdom, courage and love passes away at a moment where the world holds its breath and seems to be shaped by terror, hate and intolerance? I think the legacy Gunnar leaves behind is one that should commit all of us, independently of our origin and denomination and place of residence, not to give up our struggle for understanding, equal rights and the respect and love for each individual human being.

Dr. Andreas König
World Health Organization, Geneva

A Turning-Point Conference

"All people have fundamental moral and constitutional rights."
The Community Imperative, 1979

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To receive a full conference packet, including the registration form, contact: www.communityimperative.org
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TASH: The Action Starts Here ...

While it's true that the acronym TASH doesn't really stand for "The Action Starts Here," TASH members know that it is TASH's clarity of vision and willingness to take action that distinguishes us from many other groups.

Throughout our now 26-year history, TASH has led the way to assure that:

- the rights of people with disabilities are protected;
- progressive research is assured the support and audience it deserves; and,
- individual and legislative advocacy is available whenever needed.

We need your help to support and sustain the critically important work that TASH has begun. Please consider a contribution or a plan for giving that will secure the future of TASH's daily action toward progressive supports and inclusive lives for all people with disabilities.

Gifts may be made by check or credit card. All gifts -- regardless of the amount -- will be greatly appreciated. No amount is too small.

Do also consider:

- ***Contributions of stocks or securities***
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Charitable gifts are tax deductible. To discuss your options for making a donation to TASH, or to request a copy of TASH's Charitable Giving brochure, please contact Nancy Weiss at 410-828-8274, ext. 101.

Thank you for your assistance in securing the rights of all people to live and participate successfully in the community!

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

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Attitude, educational practices serve as barriers to friendship

BY ZACH ROSSETTI and CAROL TASHIE

Advocates for inclusive education typically cite friendship as a primary benefit and outcome of inclusive education. When all students are educated together, natural connections between students with and without disabilities result. It is a rare presentation or article on inclusion that neglects to include a story of students who developed relationships as a result of attending school together.

While friendship is an enormous benefit of inclusive education, there is growing concern among families and educators that too many students who are in regular education classes still do not have the rich and fulfilling social lives they desire. Students themselves are more blunt; they say "I don't have any friends."

If we believe friendship is an essential element of a fulfilling life, and the only way students will be able to develop friends is to be educated alongside each other, then we must ask the question: If everyone agrees this is so important, then why do so few kids with disabilities have real friends?

To answer that, we have spent time talking to students and families, and observing and working in schools where students with disabilities are educated in general education classrooms. As a result, we strongly believe that the answer to this question is never rooted in the student. It is a by-product of the attitudinal and educational practice barriers that continue to exist in society and schools, even in many schools that consider themselves inclusive.

Attitude barriers hinder real progress

Disguised as compassion, the stigma of disability is often not recognized as prejudice by the general public or even by many schools. When pressed, many teachers still do not recognize the gifts and talents of students with disabilities, or believe these students could develop reciprocal and satisfying relationships with their classmates. These long-standing prejudices serve as attitude barriers that significantly impact how students with disabilities are perceived and treated in schools, and decrease the likelihood students with disabilities will be valued and sought after by their classmates.

Educational practice barriers

When asked, students candidly report that many of the educational practices in schools — even schools that consider themselves inclusive — are genuine barriers to the development of friendship between students with and without disabilities. Students cite the continued use of pull-outs, obvious low academic expectations, Ineffective and age-inappropriate curriculum modifications, the prevalence of "inclusion rooms," the over-use of paraprofessionals, and the culture of benevolence toward students with disabilities, as real and seemingly insurmountable barriers to forming relationships. It is obvious that these educational practice barriers are manifestations of the prejudiced attitudes still held by many people and are antithetical to best practices and inclusive education.

Strategies to facilitate friendship

Answering the question: If everyone agrees this is so important, then why do so few kids with disabilities have real friends? is our goal. Acknowledging and challenging the attitudinal and educational practice barriers is essential, but it is also important that schools and families not wait until barriers are overcome before they help students develop the kind of relationships they want and deserve. Therefore, we will attempt to provide readers with concrete strategies that can be used to facilitate the development of relationships for the students they know and love.

Crucial to overcoming barriers and developing strategies is the belief that people are people first. Students who have disabilities must be equally valued just as they are; they do not need to be changed or fixed. Having a disability is a difference like any other human characteristic. It is not a deficiency. It is by no means a tragedy and does not deserve pity or benevolence or charity. Now is the time to recognize and celebrate disability rather than ignore, devalue or use it as justification for a less-valued life.

Reject the notion that some students must leave the classroom in order to learn. Object to inclusion in name only by challenging the concepts of "inclusion rooms," "inclusion teachers," and "inclusion students."

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Attitude, educational practices serve as barriers to friendship

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Attitudinal barriers to friendship may be manifestations of beliefs about the capabilities and potential of people with disabilities. But classrooms and schools should not mimic these beliefs in practice, they should improve on them.

The first step in facilitating true friendships for students with disabilities is believing that the student is someone with whom others would want to be friends — someone who would make a great friend. When teachers and families believe this, and communicate it to others in words and deeds, then the promise of friendships will be more easily met.

What do you think?

Do you have ideas for how students with disabilities in inclusive settings can be more successful at forming real friendships? Have you already had success? If you are interested in sharing your experience, please contact Zach Rossetti or Carol Tashie at the e-mail addresses below.

Zach Rossetti and Carol Tashie are with the University of New Hampshire's Institute of Disability. They have worked with students, families, and schools on strategies to facilitate friendships for students with disabilities.

If you would like to share your experiences in facilitating friendships, or if you have comments about this article, the authors may be contacted by e-mail at <zsr@cisunix.unh.edu> or <ctashie@cisunix.unh.edu>

Build foundation for friendships: Recognize, overcome attitudinal barriers

By Zach Rossetti and Carol Tashie

Here are some suggestions on how you can avoid and overcome some of the barriers that make it less likely students with disabilities will have rich and fulfilling social lives:

Prejudices. All of us are subject to society's prejudices. Think about your beliefs, your experiences and the prejudices you have been taught about people with disabilities. Ask yourself how you can change the assumptions and mind-sets you still have. Listen to people who have been segregated or devalued because of the way they look, move or communicate. Talk with people who are friends, parents, siblings, lovers and colleagues of people with disabilities. Learn everything you can about the many ways people communicate, get around and show us who they are and what they know.

Friendships. Friendships are much more likely to occur when all of the people in a student's life truly believe she is someone who would make a wonderful friend. When you believe the world is a better place because this student is in it, you can begin to help others see and believe the same thing.

Get to know students for the gifts they have to offer. Believe that all students have something valuable and precious to share with you and with the people around them.

Language. Through respectful language, you can model for others that the student with disabilities is a "person first." For example, introduce a student by name first, not condition (such as "Meet Trey, who has cerebral palsy.")

By talking to and with the student in ways respectful to his age, you will show the world that all students must have age-appropriate expectations. You can role model your belief that the student with disabilities is not deficient, but simply moves through the world in a different way.

Pull-outs. Students need to be together in order to develop respect, mutual interests and real friendships. For too many students with disabilities, even those who are enrolled in general education classes, their school day still consists of pull-outs and separate lessons. Reject the notion that some students must leave the classroom to learn. Object to inclusion in name only by challenging the concepts of "inclusion rooms," "inclusion teachers," and "inclusion students."

Communication. All students have the ability to develop effective ways to communicate their thoughts and knowledge. For students who do not speak or have difficulties with verbal communication, you can advocate for augmentative or alternative means of communication.

Make it clear that you will presume competence in all people, and never assume a student who is not able to speak is unable to understand and learn. Learn to listen to all the ways a student communicates and recognize that some students use behavior as their only way to get their points across.

Tolerance. Strive for a celebration of diversity and not simply tolerance of differences. Reject the not-so-subtle message to students that "you are welcome only if you act, sound, look, think, talk like us," and send the message to all students that "you are welcome exactly as you are."

Potential. All people are people first. No one should have to conform to someone else's standards before they are told they are good enough. We all belong. We all have strengths and weaknesses and our own individual potential to be great people and to live the lives we want. With support from others, we can all lead happy and fulfilling lives and become successful adults.

Friendship is a two-way street

BY LIZ OBERMAYER

When I was asked to write this article, it was before so much happened in this country, as well as a death of one of my friends. From both of these experiences, it has made me think and appreciate my friends even more. The reason why I am saying this is because those kind of relationships are very precicious.

One of my favorite sayings is "to be a friend is to have one." I try my best to live my life on the basis of that saying. What I mean is I think if I want to have a friend, I need to be a friend to another person. I might not be able to do anything else but to listen. For most of my true friends, that may be what they need at that time.

When I used to live in Boston, I remember one of my friends was having a hard time, and she was nervous to tell me because she thought I wouldn't understand. She told me anyway because I was her friend. It is true that I didn't quite understand, but since I was her friend, I just listened to her troubles. I felt like I owed her at least that much.

Another example of this was when another friend was having a hard time, she trusted me and another mutual friend of both of ours to "cry on our shoulders." We probably didn't do anything specific to make her feel better, but we were there to just listen. With both of these experiences and many others, it made me feel good to know that I can be a friend just as they can be a friend to me.

I believe that people with disabilities will often assume that people without disabilities should be their friends, but the person with a disability isn't willing to do anything on their part to help the friendship grow. This is wrong, and if it continues this way, then the friendship will eventually die. As my friend Nancy Ward, often says "friendship is a two way street." The reason why I say that the friendship will die is because your friend will get tired because he or she isn't getting anything out of the relationship.

Just a few weeks ago, I realized that I lost something that some of my friends gave me when I left Boston. Their gift meant a lot to me. I was sad that I lost it. I also thought my friends would be angry at me for losing it, and it would destroy our relationship, which I couldn't bear to think about. Their response was the opposite. Two of my friends were sad for me that I lost something that would remind me of them. I thought to myself that, their response was truly out of friendship rather than wanting to get something out of our friendship for themselves.

Making true friends is hard work. I guess it is hard work because if you are truly deserving of a friend, you should work for it. When I was growing up, my father had a lot of friends, and they are still friends today. I thought that making lasting friendships wouldn't be an issue for me, but it is. Yes, it is true that people have always wanted to help when I moved from New Jersey to Boston and two years ago to Maryland, but what has made those friendships last and continue is the hard work it takes on both parts.

I will try to write down some ways I think help in making friends. However, don't get upset if these don't seem to work the first time you try them -- just try again. Making real, lasting friendships can be hard work, and it can also take a long time. But it is certainly worth it!

"Hints" on How to Establish Friendships

- Find someone you share something in common with like hobbies, work, or volunteer activities.
- Always remember to treat the person how you would like to be treated.
- Relationships don't always mean sexual relationships. You can get to be good friends with people of the opposite sex.
- Be patient. Friendships can take a long time to make.
- Sometimes, if you can, you need to be brave enough to make the first "move," and ask the person if you can get to know them. This is extremely hard for me and I bet for others, but remember making friends is hard to do.

Liz Obermayer is a member of the TASH Executive Board of Directors, and a person with a developmental disability.

Stanley Herr helped write the Maryland State law prohibiting executions of persons with mental retardation.

On September 24th, the disability and legal communities lost a true friend and staunch advocate of the rights of people with disabilities.

Stanley S. Herr, a University of Maryland law professor who helped establish the federal law requiring appropriate public education for children with disabilities, has left an enduring legacy for his lifelong commitment to equality for people with disabilities.

Through his work as a lawyer, professor, and scholar, Dr. Herr's advocacy and service were instrumental in helping to shape disability law, and have inspired commitment in other lawyers to public service and disability rights. His work in the seminal cases of Mills v. Board of Education and Wyatt v. Aderholt, his public service as a law professor at the University of Maryland School of Law, and his involvement with the Civil Rights of Persons with Disabilities Seminar, workshop, and clinic have each had significant impact in improving the lives of people with disabilities and changing the landscape of disability rights law.

Mills v. Board of Education was a District of Columbia suit establishing a constitutional right to a publicly supported education for all school-age children regardless of degree of physical, emotional, or mental disability. Congress and the Supreme Court cited Mills as providing the legal and political roadmap for the 1975 National Education for all Handicapped Chidren Act (the Act that was the predecessor to the IDEA). Wyatt v. Aderholt was an Alabama suit affirming the constitutional right to treatment for persons with mental illness and retardation confined in state mental institutions.

Dr. Herr's landmark legal efforts included helping to write the 1989 Maryland law that prohibits the execution of criminals labeled as having mental retardation. He also submitted a brief that was cited by the Supreme Court in abolishing the death penalty for people with mental retardation. In the early 1970s, Dr. Herr played a role in cases that freed people with disabilities and mental retardation from long-term institutional placements.

Dr. Herr was an authority on retardation and mental illness who wrote extensively on the subject -- five books and 100 articles on disability rights, elder rights, children's rights and human rights topics.

Earlier this year, Dr. Herr was awarded the Paul G. Hearne Award for Disability Rights for his work championing the rights of people with disabilities. Among his many recognitions, there are two that will ensure that Dr. Herr's legacy will continue. The University of Maryland School of Law has established the Stanley S. Herr Fund for Disability Rights and Social Justice to allow scholars with national reputations to visit the school. The BARC (Baltimore Association of Retarded Citizens) created the Stanley S. Herr Award for Advocacy Leadership to honor future advocates for people with developmental disabilities.

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Personal Relationships Between People With and Without Disabilities

BY ZANA MARIE LUTFIYYA

Friendships between people with and without disabilities enrich the lives of both in many ways. Everyone needs friends. Friends are people who support us emotionally, who see things from our point of view, who give us feedback (sometimes critical) and cause us to grow. We think of our friends as people who choose us for ourselves, not because they have to, and who will be there for us when we are facing a crisis. With friends, we have opportunities to become involved in community and school activities, to be exposed to new experiences, and to enjoy life more fully.

If we want the people we love to be connected to others and a part of their society as adults, we must think about their relationships when they are children. Their classmates and neighbors will grow into their coworkers and friends later in life. Integrated classrooms and recreational activities are important first steps: in these settings children with and without disabilities get to meet each other. But many parents have found that even though their child is integrated in school, she or he has few friends who do not have disabilities.

Many individuals with disabilities live largely in a world made up of their family, the people who support or provide services to them, and others in the programs in which they participate. These relationships can clearly be significant and should be encouraged. But outside of family members, people may have no freely given and chosen relationships.

Generally, many people with disabilities face certain disadvantages in getting to know others and forming connections:

❖**Opportunity**. Too many people with disabilities have limited opportunities to take part in activities where they can meet their typical peers. This can be due to physical segregation, or to the individual not being empowered with the choice of determining how or with whom he/she chooses to associate. Services may restrict people's chances to get together, through program or funder rules, curfews, transportation restrictions, and other restrictions. Whatever the reason, people with disabilities frequently become cut off and isolated from others.

❖**Support**. Relationships between people with and without disabilities are not formed by throwing unsupported people together. Some individuals need assistance with fitting into certain settings and activities. Others may need someone to facilitate their involvement or to interpret them to others in positive ways. Without subtle supports, people with and without disabilities might never get a chance to really get to know each other.

❖**Continuity**. While we enjoy meeting new people, we are sustained by those we have known over time. The continuity of our relationships over the years is an important source of security, comfort, and self-worth. Many people with disabilities do not have continuous relationships: they may leave their families, be moved from one program to another, and have to adjust to staff people who come and go.

Personal relationships between people with and without disabilities can be facilitated in a number of ways. It takes effort to help people establish connections. Described below are some of the methods that have been utilized:

○ **"Bridge-Building"**: Facilitators who initiate, support, and maintain new relationships are called bridge-builders, as they "...build bridges and guide people into new relationships, new places, and new opportunities in life." Bridge-builders involve people with disabilities in existing groups or with specific individuals.

○ **Circles of Friends or Circles of Support**: Groups of people who "meet on a regular basis to help a person with a disability to accomplish certain personal visions or goals." Circle members try to open doors to new opportunities, including establishing new relationships.

○ **Citizen Advocacy**: Recruited and supported by an independent citizen advocacy office, a citizen (advocate) voluntarily represents the interests of a person with a disability as if they were the advocate's own. Citizen advocates may take on one or several roles (e.g., friend, ally, mentor, protector), and some of these may last for life.

There are different ways that personal relationships between people with and without disabilities may be encouraged. Perhaps more important than the specific method is the supporting, connecting role of one or more people – family members, staff members, friends – who can spend time and energy for this purpose.

Continued on page 26

Personal Relationships Between People With and Without Disabilities

Continued from page 25

There are different ways that personal relationships between people with and without disabilities may be encouraged. Perhaps more important than the specific method is the supporting, connecting role of one or more people—family members, staff members, friends, etc.—who can spend time and energy for this purpose.

There are some important dimensions of friendships that develop between people with and without disabilities. Genuine friendships between these individuals do exist. While each friendship is unique, there are some shared ideas and expectations about what friendship means. According to a study of pairs of friends (Lutfiyya, 1990), these meanings include:

Mutuality. The people involved defined their relationship as a friendship and themselves as friends. Although they acknowledge differences between themselves, they clearly found a sense of mutuality in the friendship. Mutuality was expressed in the giving and receiving of practical assistance and emotional support, and enjoyment of each other's company.

Rights, Responsibilities, and Obligations. Once a friendship is established, it is assumed that friends can make certain demands on each other and be assured of a response. In these relationships, the persons without a disability talked about the obligations that they had taken on vis-a-vis their friend with a disability, such as teacher, mentor, or support person. The friends with disabilities perform certain responsibilities in maintaining the relationship: keeping in touch, suggesting possible activities, and so on.

Feelings, from Companionship to Intimacy. All of the friends held feelings of affection for each other, expressed through their actions and how they spoke with each other.

Freely Chosen and Given. Friends choose each other. It is this voluntary aspect of friendship that is regarded as the amazing and wonderful part of the relationship.

Private and Exclusive Nature. Within the boundaries of each friendship is a private relationship that is not accessible to others. The friends have a history and an understanding of their connection to each other that separates this from all of their other relationships.

People can establish friendships with each other, but it is not possible to create friendships between others. However, it is possible to create opportunities for people with and without disabilities to meet and spend time with each other in ways that encourage friendships to take root and flourish. Families and service providers can do different things to make such opportunities available.

Families can:

Work for the total inclusion of their son or daughter into the regular school system. In addition to being physically present, students with disabilities need adequate supports for the fullest participation possible. Parents can also insure that their child with a disability takes part in a variety of integrated recreation and leisure activities after school hours. A consistent physical presence in each others' lives is a necessary foundation for friendship to occur.

Insure valued social participation. How people with disabilities are supported within integrated settings is important. Students need to be empowered to participate as much as possible, and to do so in ways that other people value and appreciate. People without disabilities need the opportunity to meet their counterparts with disabilities as peers, not as tutors or volunteers.

Involve and trust others. All parents feel protective toward their children. While there may be differences in how independent people can become, parents can come to believe that there are people in the community who would, if given the opportunity, enjoy and welcome a friendship with their son or daughter.

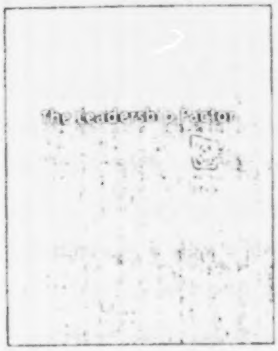
Service providers can:

Reduce barriers to friendship. The way in which support services are provided to people with disabilities and their families can enhance or reduce the opportunities for friendships to develop. By offering segregated programs, the service system dramatically lessens the chances for contact between people with and without disabilities.

There are also problems within integrated settings. For example, transportation from school often means that students with disabilities cannot take part in extracurricular activities (e.g., choir, clubs, sports). When efforts are made to bring people with and without disabilities together, the people without disabilities are often treated as volunteers responsible to the teacher or program coordinator rather than as peers.

Many other human service practices present barriers to development of friendships, such as curfews, lack of communication with friends about a person's plans for a day, lack of privacy, and so on. Service providers can begin by recognizing and reducing the practices which curtail opportunities for people to meet and form friendships with each other. They can also encourage people who seem to like each other to pursue the possibilities.

Reprinted with permission of author. Dr. Zana Marie Lutfiyya is an associate professor in the Department of Educational Administration at the University of Manitoba, Winnipeg, Manitoba, Canada. Comments about this article, or questions about resources related to personal relationships by and with people with developmental disabilities may be directed to Dr. Lutfiyya via e-mail at lutfiyy@ms.umanitoba.ca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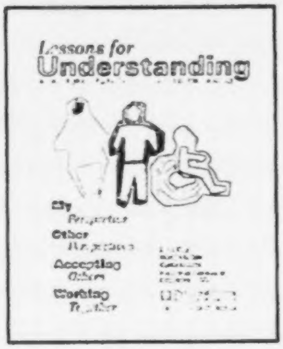
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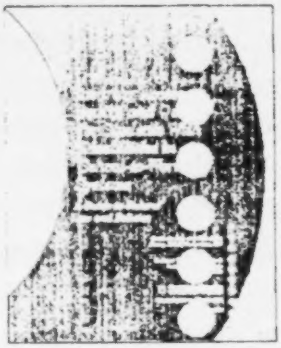

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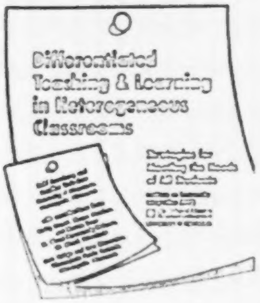
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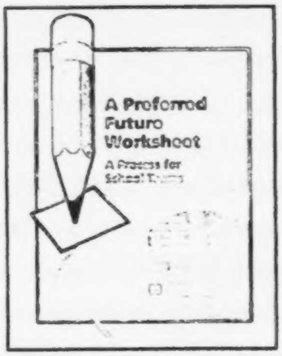
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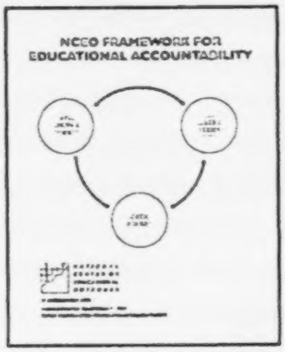
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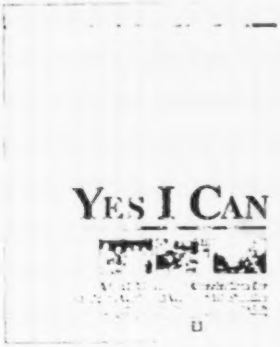

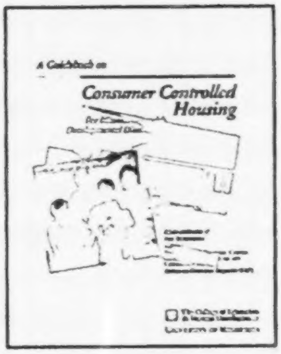
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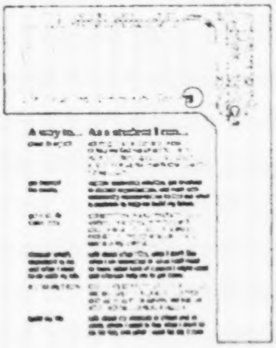
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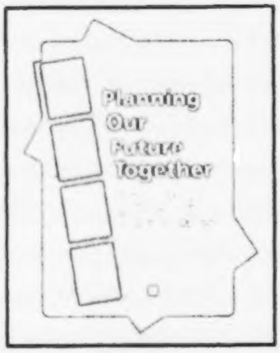
Planning Our Future Together

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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TASH CONNECTIONS

Equity, Quality and Social Justice for People with Disabilities

Inside This Issue

- **Updated TASH Mission Statement**
- **Literacy Opportunities for Young Children with Developmental Disabilities**
- **Early Childhood Intervention Personnel Preparation**
- **Inclusive Childcare Settings**
- **TASH Resolution Opposing the Execution of Persons Labeled as Having Mental Retardation**

Issues in Early Child Care and Education

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Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

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WHOM DO I CONTACT?

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- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Meetings and Technical Assistance, at (410) 828- TASH, Ext. 103, e-mail:dmarsh@tash.org
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- **Don't forget to visit TASH's web site at http://www.tash.org**

TASH: Public Policy in Action

TASH Early Childhood Committee Sets Policy Agenda

Members of the Early Childhood Committee and conference participants met during the TASH 2001 Conference and developed the following recommendations that should be incorporated into all policy, programs, and research initiatives developed by the U.S. Department of Education.

1. Policy and fiscal resources that support environments where all young children, with and without disabilities, learn and grow together need to be given priority.

2. Services, supports and information provided to the families of infants, toddlers and young children must be widely available and easily accessible in every community.

3. Information that could benefit families of infants, toddlers and young children with disabilities should be disseminated within the community environments frequented by all families (e.g. pediatrician's office, supermarkets, libraries).

4. Families should be full participants in the research process because they are the intended beneficiaries. Funding priorities should support family-researcher partnerships at all stages of the research process.

For more information about the work of the TASH Early Childhood Committee contact:

Elizabeth Irwin, Ed.D.
Committee Chairperson
Queens College of the City University of New York
Phone: (973) 744-3975
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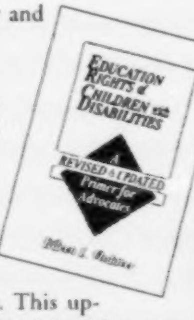
Education Rights of Children with Disabilities
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Education Rights of Children with Disabilities: A Revised and Updated Primer for Advocates is a basic legal reference designed to assist parents, students, and their advocates in securing rights to quality preschool, elementary, and secondary education guaranteed by the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and Title II of the Americans with Disabilities Act. Education Rights of Children with Disabilities:

- Discusses rights under the statutes and their regulations, along with remedies for their violation.
- Includes extensive citations to judicial decisions and U.S. Department of Education interpretations of IDEA and Section 504 requirements.
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-- the right to learn in the general curriculum;

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-- rights of children with behavior that challenges schools;

-- transition from early intervention to preschool services; and more!

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To sign up for the Government Relations listserve or for information about specific policy issues or legislation, contact Jamie Ruppmann, Director of Governmental Relations, at (410) 828-8274, ext. 104 (voice) or by e-mail <jruppmann@tash.org>

What's in a Name? The Story Behind the Name Change That Never Happened

The Background

I am sure by now most of you have heard that the long and arduous process of deciding on a name that the letters T-A-S-H can stand for ended in keeping it as TASH (just TASH, without the letters standing for any words) and with the possibility of a tagline. Many of you probably are confused and so I will try to tell the condensed version of the story so that everyone knows how all of this came about. My history with the process of changing TASH's name to one that is meaningful and acceptable to all its members is short, but I will try here to do it some justice.

By way of a bit of history, when TASH was started in 1974, it was called the American Association for the Education of the Severely/Profoundly Handicapped and went by the acronym: AAESPH. In 1980 the name was changed to The Association for the Severely Handicapped, reflecting TASH's broader mission. The name was changed to The Association for Persons with Severe Handicaps in 1983, but the acronym TASH continued to be used. In 1995, the Board voted to maintain the acronym because it was so widely recognized but to stop using the full name of the organization because it was clear that the word "handicapped" was no longer an acceptable term to use.

For a number of years now TASH has just been "TASH" with a descriptive tag line. Often, people ask what the T-A-S-H stands for and it is necessary to explain the history behind the name. During this period, people often have still used "The Association for Persons with Severe Handicaps" to explain what the letters in TASH stand for because there was nothing else to substitute. Some people feel that explaining the various name changes has been a good way to inform people about changes in language and values; others have found the explanation to be cumbersome; some have found the name useless in its lack of descriptive words; others have found it lacking vision.

Donna Gilles
President, TASH Executive Board

The Current Name Change Effort

The current phase of the name-change effort started several years ago. Four years ago I was elected to the Executive Board. At my first board meeting, one of the agenda items was the "Name Change." This agenda item was addressed for a surprisingly short period of time given its importance and given that I know now that no Board meeting agenda item ever results in a shortage of discussion! As a new Board member without enough information to understand the reasons, I was taken by the speed with which Board members suggested dropping the subject after one person would make a statement about the direction the name should go and almost simultaneously another would remind him or her of the opposing opinion — end of discussion. I can only imagine how uncomfortable, threatening, and ultimately punishing previous discussions had been to stop a dialogue as important as this so quickly (so much for our commitment to positive approaches and collaboration!). This scenario of avoiding the topic altogether was ongoing for the next several meetings. However during this period, a very organized effort was undertaken to collect information and opinions from the membership about what TASH should be called, what TASH's focus is and should be, and what functions TASH as an organization does and should perform.

At the conference in Miami in 2000, the Board once again discussed how to proceed with the name change, acknowledging the diversity of thought on the matter based on some 250 responses to surveys and requests for comments received and analyzed by the TASH staff. At the end of the discussion, we came up with a plan to use a committee process to rework the mission statement and identify a new name. We were determined to first figuring out what TASH as an organization is and should be about (our mission) and then choosing a name to reflect that commitment. The Board also voted that if "TASH" were to be the name, it had to be an acronym (the letters had to stand for words); our name couldn't just be "TASH". I asked Patrick Schwarz to co-chair this committee with me because together we represented two different perspectives on the name change issue which, hopefully, would guarantee fair representation of the diversity of thought throughout the committee process.

The Process

The committee membership comprised the Executive Committee of the Board and other board members who wished to volunteer. Patrick, Nancy Weiss, and I then generated a list of leaders in the organization who had expressed varied opinions about the name of the organization and who, hopefully, would equitably represent the diversity of opinion. The committee met and developed three subcommittees: one to rework the mission to be better defined, one to identify criteria against which proposed names could be measured, and one to strategize and implement ways to involve more people with disabilities in the name change process. All three subcommittees were successful. The first subcommittee drafted a new mission statement that is clear about what TASH's focus is and what function TASH should serve (see TASH's new Mission Statement on page 6). The second subcommittee developed suggested criteria that included:

- Length - The name should not be overly cumbersome
- Descriptiveness - The name should communicate clearly who we are and what we do
- Inclusive of the diversity of the perspectives of our members and potential members
- Using language that self-advocates (or others) do not find objectionable
- Consistent with the principles and mission of the organization
- Maintains the acronym TASH if possible
- If we use the acronym "TASH" it needs to stand for something. Having "T-A-S-H" with a tag line isn't acceptable (note: having a tag line would be OK, but not having just

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The Story Behind the Name Change That Never Happened

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T-A-S-H be the name, not standing for any specific words, with a tag line)

- Shouldn't be too similar to the acronym of another disability organization so as to be confusing

The third subcommittee generated a list of members with disabilities who were invited to participate in the name change process, and shortly after, those individuals were invited to all subsequent committee meetings.

Once the subcommittees completed their work, the full committee was charged with generating several names that would be submitted to the Board for a vote. The full committee completed that work shortly before the 2001 conference in Anaheim. In order to get a feel for which of the proposed names conference attendees liked best, they could get a sticker (or two or ten, as it turns out) and place it next to the preferred name and/or could write in what they considered a better name. At the strategic planning meeting on Saturday at the conference, several issues regarding the name change came up which led to the Board vote on that same afternoon to keep the name as TASH, not an acronym, and to invite the name-change committee to draft a tagline to accompany the name.

Two things were obvious from the issues that were discussed at the strategic planning meeting. First, we as the participants in this name-change process did not keep the membership informed every step of the way about the issues that were driving the various opinions about the name. For that, I apologize. People who were not involved with the name change committee's work never had the same luxury, as we did, of working through the issues with those who feel differently yet equally passionate about the name of the organization. Second, it was very clear that there is a perception that because there is a difference of opinion on what the organization should be called, there is also a serious difference of opinion about what this organization's mission should be. This will be discussed later.

The Issues - A Snapshot

The Language

The language of the organization's name has generated the most controversy. It seems to come down to two motivations: one appears to target the means (e.g., "who" we represent or "how" we do our work), the other clearly targets the end (the results of our work). Many people who sent in comments during the survey period opposed having a name that highlights social justice and/or human rights because it might be interpreted as TASH trying to be all things to all people, thus diminishing its focus on people who are labeled as having severe disabilities. Interest in having the name reflect the people for whom we are advocating is based on the real experience of professionals and family members who have seen the issues of children and adults with the most intense support needs get lost in the competition for better services, better supports, better lives. It is seen in our schools where the students labeled "severely disabled" are least likely to have access to the general education areas of the school let alone the general education curriculum. It is observed in our communities where, despite supported employment initiatives, the adults who need the most support to work at real jobs are still spending their "working" day at sheltered workshops or worse; and where, despite the supported living initiatives, people with significant needs are most likely to live in congregate arrangements.

Some TASH members expressed concern that people, members and non-members, would not look beyond the name of the organization to the mission statement to get an accurate idea of what TASH is about. Many people were concerned that without the word "severe' in the organization's name, TASH's critical focus on people with the most significant needs would be lost.

Many people are concerned that maintaining a title that targets a population does not describe what we do with and in support of those individuals or our vision. TASH is known for its commitment to the following:

- moving people out of institutions and into homes of their own with the support they need;
- moving children out of dead-end classrooms and segregated schools to inclusive educational settings with the support they need;
- moving adults out of sheltered workshops to real work with the support they need;
- eliminating the use of abusive and sometimes deadly techniques to control behavior in the name of treatment and replacing it with positive behavior support strategies.

So, the question from some people who target the "end" or the outcome might be, "What do we do that isn't working toward social justice? All that we do to support progress for people with the most significant needs is, in effect, social justice work."

The issue of using the word "severe" in the name has been a hot spot in the discussions. There are several issues surrounding the use of the word "severe." First, the word itself outside the context of disability connotes serious, grave, bad, catastrophic. A severe storm means potential destruction; a severe drought equals loss of food; severe illness, hospitalization. There is nothing positive about the word.

Second, it is a label that tends to be deficit oriented. It is awkward, to put it politely, to support the empowerment of people who have significant support needs and at the same time label them as if they can never achieve self-determination. Third, the definition of "severe disabilities" is nebulous. The perception of who has a severe disability and who does not differs from person to person and the term is viewed as an exclusionary or discriminatory term by some.

We all have our image of who can be described as a person with severe disabilities. In fact, even those who find the term unacceptable to use in the organization's name continue to use the term to describe a population of individuals. And so begins the slippery slope of descriptive language.

Continued on page 26

TASH MISSION

TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society;
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH**'s mission; and,
- Promoting communities in which no one is segregated and everyone belongs.

Congratulations

to the following newly elected members of the

TASH EXECUTIVE BOARD

Tracy Knight
Jorge Pineda (re-elected)
Patrick Schwarz (re-elected)
Jeff Strully

◆ ◆ ◆ ◆ ◆

We also extend congratulations and best wishes to Fredda Brown, the new Editor of JASH

TASH's work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous support of our newest lifetime member

Jeffrey L. Strully ~ Mission Hills, California

Lifetime membership entitles you to full international and chapter member benefits for your lifetime. The cost can be remitted over several monthly payments.

If you are interested in becoming a lifetime member of TASH, please contact Rose Holsey at 410-828-8274, ext. 100.

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Thanks, too, to the gracious donations of the following individuals and organizations:

ADAPT of Texas
Meredith Akers
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Christin S. Cooper
Larry Douglass
Anne Donnellan
Gary Goldwater
Mary Hoskin
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Amy Sharp
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Marti Snell
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Michael Williams
Joe Wykowski
Michele Flasch Ziegler

YOUNG CHILDREN'S CITIZENSHIP IN THE LITERATE COMMUNITY:

Significant Disability and the Power of Early Childhood Inclusion

BY CHRIS KLEIWER, LINDA MAY FITZGERALD, AND DONNA RASCHKE

The Clemente family includes Paulo, Jr., a bright-eyed five-year-old with a love for firefighters and -- because of his older brother's gridiron exploits -- a passion for all things football. "They wanted him to be in the 'moderate room,'" Paulo, Sr. explained in a recent interview.

He was referring to school district personnel who had tried to steer the Clemente family toward placing the younger Paulo in a segregated primary grade special education program following two years spent in an inclusive preschool. Paulo, Jr. was born with cerebral palsy and has multiple disabilities. He primarily communicates through symbol choices, eye gaze, and body movement.

"They had nothing for him there," Mrs. Clemente interjected, referring to the "moderate room," the room's moniker actually used by education personnel. "At his preschool they had books, play, dress up. Not there [in the moderate room]." Had the Clementes bowed to professional pressure, young Paulo would have found himself in a classroom nearly devoid of materials and activities commonly associated with kindergarten and primary education - including books and opportunities to play and learn to read!

The Link Between Literacy, Dramatic Play, and Inclusion

The phrase "books, play, dress up" used by Mrs. Clemente is quite profound. In our observational studies of literacy learning for young children with significant disabilities, we've stumbled upon an interesting, intertwined set of phenomena: When dramatic play is a taken-for-granted part of the educational environment, so too are consistent opportunities for children to engage and use printed language in varied formats. This appears to be a transactional relationship: Literacy supports dramatic play supports literacy supports dramatic play supports literacy, and so on.

Further, for young children with significant disabilities, dramatic play as a taken-for-granted part of the environment occurs almost exclusively in inclusive situations. Hence, meaningful and rich literacy opportunities for children with significant disabilities are also most often found in inclusive settings. There's little that is absolutely essential to the above interrelationships. For instance, a teacher in a classroom segregated for young children with high-level support needs could set up a dramatic play area. He or she could create a corner library. But in classrooms organized entirely around the notion of severe disability, this appears to rarely occur.

Research suggests that play and literacy opportunities together are fundamental to the development of a child's critical thinking abilities, higher-order thought processes, social interaction skills, and other important human capacities. Yet, for young children with significant disabilities, access is often severely curtailed based on the assumption that critical thinking and higher-order thoughts are either far, far away or even an impossibility.

For young children with significant disabilities, the link between inclusion, literacy, and play originates in surrounding attitudes and practices. Early childhood education personnel who understand that inclusion is a civil right begin with the premise that the young child with significant disabilities will participate as a full citizen of his or her natural (to use IDEA language), or nonsegregated, environments. In contrast, conventional education attitudes that support segregation demand that participation with nondisabled peers wait until the child approximates some version of normality as generally determined on developmental assessments. In this sense, inclusion demands children first prove themselves cognitively, socially, communicatively, and in other developmental domains.

Literacy and play, like inclusion itself, are conventionally linked to cognition and general development. The equation demands that children first prove themselves developmentally, and only then will opportunities for use of imaginative play and printed language be offered. In inclusive environments, however, participation is the premise and the expectation. Citizenship in the classroom community also means citizenship in that class's literate and play community.

The Relationship Between Dramatic Play and Literacy

In our culture, the importance of dramatic play and early literacy experiences is universally accepted -- provided the child does not have significant disabilities! The image of a child sitting on her father's lap

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THE IMPORTANCE OF LITERACY OPPORTUNITIES FOR CHILDREN WITH SIGNIFICANT DISABILITIES

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reading a book, or laying on his stomach watching Sesame Street, or acquiring her own library card, or wearing a plastic firefighter's helmet while running wildly with stick in hand, looking for the nearest pretend fire, are all understood to be fundamentally important aspects of healthy development.

Books, visual literacies, and dramatic play wrench young children from the immediate here-and-now; they allow children to transcend their own experiences and explore the realities of other's, whether that be through the eyes of Max, King of all Wild Things, through the ears of the elephant, Horton, who hears what others cannot, through the adventures of a very hungry caterpillar, or through situations self-created with a few props.

Research suggests that play and literacy opportunities together are fundamental to the development of a child's critical thinking abilities, higher-order thought processes, social interaction skills, and other important human capacities. Yet, for young children with significant disabilities, access is often severely curtailed based on the assumption that critical thinking and higher-order thoughts are either far, far away, or even an impossibility (which may in fact turn into a self-fulfilling prophecy as professionals eliminate the very opportunities necessary for the development of these various capacities!). Deep, meaningful engagement with printed language is restricted. If symbols are used at all, the focus is often solely on the child getting immediate needs met. Nothing is wrong with communicating immediate needs; the dilemma is what gets left out.

Multiple Literacies in the Inclusive Early Childhood Classroom

In a recent observation conducted in a preschool inclusive classroom made up of four-year-old students, we watched as a restaurant scene unfolded. In the center of the room, teachers had arranged a few tables with salt shakers, plastic utensils, and various menus borrowed from local establishments.

Several children sat at the tables, pouring over the menus, shouting out orders to a "waiter" who jotted down the various requests on a pad, but with tremendous editorial control. "I want the hamburger," one student yelled. "You get the pizza," the waiter explained, scribbling furiously on his pad. "How much is my meal?" another student asked, grabbing a stack of fake money. "Eight hundred dollars," the waiter responded. "I don't have eight hundred dollars," the patron retorted. "Then you're out of the restaurant!" the waiter yelled. "I don't have eight hundred dollars either," another customer said. "Then you're kicked out too," the waiter responded.

In the above scenario, literacy was an integral part of the dramatic play, from reading menus, to taking orders, to using the pretend money. Also, similar to the experience of engaging with a book, this dramatic play allowed children to transcend the immediate here-and-now. They explored and took on the roles of others. As the drama unfolded, we watched Jason sit on the periphery of the play, piecing together a jigsaw puzzle. Jason is four, has a label of autism, and entered the school year considered to be nonverbal. In the intervening three months, Jason had begun speaking -- first by reading text out loud, and more recently making spontaneous utterances.

Jason appeared extremely intent on the restaurant play. Eventually, one of the patrons, kicked out of the restaurant by the dictatorial waiter, stumbled over Jason and the two rolled on the floor, giggling until a teacher cut short the roughhousing. The boy continued on, and Jason stood, and walked to one of the tables. He sat and picked up a menu, holding it upside down. A passing teacher noticed, stopped, turned the menu over in Jason's hand, and said, "What are you going to order? What're the choices?" With the teacher's hand over his, Jason pointed to the word hamburger (which had a picture of a hamburger next to it). He quietly voiced, "Hamburger." They repeated this with several choices. The teacher said, "Okay, what're you going to order? Oh waiter, we're ready to make an order." The waiter appeared, pad and pen poised, and waited while the teacher quietly voiced in Jason's ear, "I want to order the ...," Jason finished the sentence, "Hamburger." "Hamburger," the waiter said, scribbling into his pad, "That'll be eight hundred dollars please." In a few moments, Jason, like every other patron, had been kicked out of the restaurant for lack of money.

Jason's participation as a literate, rightful citizen of the inclusive preschool classroom creates opportunities for meaningful dramatic play, friendship, serious curricular encounters, cognitive and social development, and so forth. His teachers are adamant that he and two peers also labeled with disabilities are fully involved in the many ways literacies are structured in inclusive early childhood programs.

The University of Northern Iowa was recently awarded a three-year U.S. Department of Education Directed Research Grant to study literacy development in young children with

> *[Teachers need] to recognize multiple literacies and open a range of opportunities to children. For instance, art of all kinds has been a valued form of symbolic expression since prehistory, and in every culture on earth. For children with significant disabilities, however, art has commonly been denied.*

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THE IMPORTANCE OF LITERACY OPPORTUNITIES FOR CHILDREN WITH SIGNIFICANT DISABILITIES

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severe disabilities. Entitled *The Young Child's Citizenship in the Literate Community,* preliminary findings suggest that effective early childhood educators have a set of purposes when structuring literacies throughout the classroom. These purposes appear to include:

❖**Transcendence:** Literacies structured to move the child from the here-and-now in order to explore roles and "walk in the shoes of others."

❖**Relational:** Literacies structured to build understanding between adults and children, and between children and their peers.

❖**Communicative:** Literacies structured to promote interaction on the part of children.

❖**Skill Building:** Literacies structured to promote the development of further, specific phonic-literacy skills and other curricular abilities.

❖**Interpretive:** Literacies structured to convey ideas and promote understanding.

❖**Control:** Literacies structured to promote regulations, rule-following, and to impose limits.

Again, this set of criteria is preliminary, and most likely will change as our research unfolds. Still, it is this sense of multiple literacies that Jason, as a member of an inclusive class, is an integral part of. It is precisely this complexity of which the Clementes demanded young Paulo be a part.

Supporting Young Children with Significant Disabilities as Citizens of the Literate Community

Because of delimiting and restrictive behaviorist traditions in special education, including in early childhood special education, IEP and IFSP(Individual Family Service Plan) goals and objectives tend to be written as countable or measurable outcomes. It is difficult to put into concrete developmental sequences the subtle qualities of, for instance, dramatic play. Hence, education plans commonly ignore these most vital of opportunities we can make available to young children. Creative early childhood educators, however, find ways to slip the surly bonds of behaviorism in order to focus efforts on more meaningful issues of citizenship.

In addition, we've begun to explore and uncover certain apparently important themes related to citizenship in the inclusive classroom's literate community for young children with significant disabilities. These include:

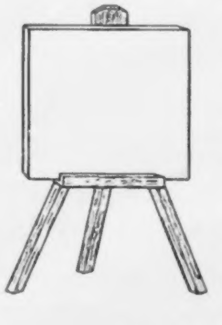
- The need for teachers to recognize that children's social engagement with one another drives the development of symbolic capacities. This means that rather than waiting for "proof" of competence (as "articulated" by the child through symbolic capacities) prior to opening complex social and play opportunities, children's actual participation in those opportunities is the terrain on which symbolic competence will ultimately be realized.

- The need for teachers to structure symbols and print as communication. This includes as a part of actual communication systems, but also means through such activities as role plays and drama activities in which children are expressing thoughts and ideas to one another.

- The need for teachers to be willing to provide unique supports for children's literacy development. Young students with, for instance, autism or severe physical disabilities may not make use of printed language in ways that conform to traditional developmental sequences. They may require technologies, physical supports, or activities that fit their particular needs.

- The need for teachers to develop comfort not knowing precisely where certain opportunities will lead a child. Many teachers have gone through preparation programs that heavily emphasize behaviorist traditions. These suggest we define exactly how a child will perform, and then we condition and chain behavior toward these predetermined ends. Such certainty is cast aside when we open dramatic play opportunities to a child, or when we read together from *Where the Wild Things Are*, yet these are opportunities fundamental to citizenship.

- The need for teachers to recognize multiple literacies and open a range of opportunities to the child. For instance, art of all kinds has been a valued form of symbolic expression since prehistory, and in every culture on earth. For children with significant disabilities, however, art has commonly been denied. This crime is based on the myth that art is nonessential and that it's too abstract for children with disabilities. This then sets up the self-fulfilling prophecy that people with disabilities have no need for the literacies of art -- which has unnecessarily denied countless people particular citizenship opportunities available through painting, drawing, sculpture, and other mediums. Paulo Clemente, Jr., introduced at the beginning of this article, is included in a regular kindergarten for the majority of the school day. Because his parents fought for his right to access the general school community, Paulo continues to experience opportunities for dramatic play, book reading, decoding skills activities, role plays, and so forth. He is a valued member of the classroom community, and is beginning to demonstrate conventional reading and typing skills. His parents and his current teacher understand he's exactly where he needs to be.



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THE IMPORTANCE OF LITERACY OPPORTUNITIES FOR CHILDREN WITH SIGNIFICANT DISABILITIES

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ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of JASH for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:

Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

Regardless of how many students join, TASH provides a year's worth of back issues of the journal to all students signing up under this plan. This means your students will start the semester with a year's worth of cutting edge research on their shelf and can build their collection over the years to come. Under this plan, students receive all of the regular membership benefits during the coming year — in addition to an extra full year's worth of journals!

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To receive materials or to learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

A Turning-Point Conference

The Community Imperative

Join Us

To reaffirm the fundamental values and beliefs that have inspired the disability rights movement; To develop and commit to long-term public policy goals in support of these values; To strengthen advocacy organizations, create alliances, and obtain the information and tools necessary to succeed.

January 25 & 26, 2002
Oakland Marriott City Center
1001 Broadway ❖ Oakland, California

California Alliance for Inclusive Communities, Inc.
C.A.I.C.

A conference for people with disabilities, family members, policy-makers, educators, direct support professionals, advocates, and other interested groups

Center on Human Policy

Co-Sponsors and Supporters include ADAPT, the Arc of the United States, the American Association on Mental Retardation, the National Coalition on Self-Determination, the Research and Training Center on Community Living at the University of Minnesota, TASH, the World Institute on Disability, and over 20 California organizations.

Featured speakers include Dion Aroner, Cliff Allenby, Hank Bersani, David Braddock, Terry Boisot, Mary Cerreto, Bill Coffelt, June Downing, Mary Falvey, Thomas Gilhool, Ellen Goldblatt, Ann Halvorsen, Scott Klassen, K. Charlie Lakin, Patricia McGill Smith, Patricia Mejia, Hector Mendez, David Miller, Pat Napoliello, Tom Neary, John O'Brien, Connie Lyle O'Brien, Mark Polit, Ruth Shelton, Bonnie Shoultz, James Shorter, Jeff Strully, Steve Taylor, Cheryl Marie Wade, David Wetherow, and Faye Wetherow

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Partial support for this conference has been provided by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education for the National Resource Center on Supported Living and Choice awarded to The Center on Human Policy, School of Education, Syracuse University.

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The Community Imperative

1979

A Refutation of All Arguments in Support of Institutionalizing Anybody because of Mental Retardation

In the domain of Human Rights:

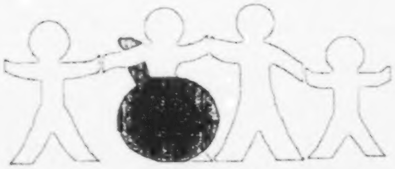
- All people have fundamental moral and constitutional rights.
- These rights must not be abrogated merely because a person has a mental or physical disability.
- Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Services:

- All people, as human beings, are inherently valuable.
- All people can grow and develop.
- All people are entitled to conditions which foster their development.
- Such conditions are optimally provided in community settings.

Therefore:
In fulfillment of fundamental human rights and in securing optimum developmental opportunities, all people, regardless of the severity of their disabilities, are entitled to community living.

Conference Vision



The California Alliance for Inclusive Communities, Inc., the Center on Human Policy, and our other local and national sponsors invite you to join us for this historic event.

In spite of enormous progress toward realizing the principles set forth in The Community Imperative declaration, California and other states are experiencing significant challenges to realizing community living for ALL people with developmental disabilities.

The California Community Imperative Conference is based on the vision of "The Community Imperative," which asserts the value of all people and the right of all people to community living. As we see it, "community living" incorporates inclusive family life, schooling, housing, work and other meaningful daytime pursuits, recreation and leisure, relationships, and other aspects of life in our communities.

At the conference, we will join with some of the leading individuals in the field of developmental disabilities, both in California and North America. We will revisit our history, focus on current challenges, and launch a continuing effort to achieve inclusion throughout the life span for all Californians with developmental disabilities. You are invited to join us in this endeavor. Together we cannot be denied.

Registration:
In order to make the conference more accessible, the registration fee is only $35 and may be waived upon request. Registration materials and more information is available on-line at www.communityimperative.org or by calling the Alpha Resource Center at (877) 414-6227

For Additional Information Contact:
www.communityimperative.org • Kim Olson at Alpha Resource Center, 1-877-414-6227 or caic@silcom.org • Center on Human Policy, Syracuse University, 1-800-894-0826, thechp@sued.syr.edu or http://soeweb.syr.edu/thechp/

TASH Recognizes Exemplary Achievement in Media with 2001 Images Awards

At its recent annual conference in Anaheim, California, TASH honored a selected group of individuals and companies for their extraordinary contributions in creating and promoting accurate portrayals of people with disabilities in the media. Recipients of the 2001 TASH Images Awards were honored for their efforts in:

- Emphasizing inclusion or civil rights aspects of issues or stories
- Supporting self-determination and/or independent living philosophy
- Promoting empowerment of people with disabilities
- Valuing the civic participation of individuals with disabilities
- Contributing to the shaping of positive images and helping to eliminate stereotypes
- Promoting accessibility
- Portraying and embracing diverse characters

We take this opportunity to salute the achievements of the following award winners, and acknowledge their contributions in promoting positive images of people with disabilities in mainstream media.

2001 TASH Images Award Winners:

Exemplary Achievement in Print:

Beth Mount
Through the years, Beth Mount's artwork, publications, and posters have served to inspire us all to realize that every person with a disability is a valuable and productive member of community life. The impact of Beth's 30-year body of work has been extensive and is known throughout the world. Her work has been instrumental in helping people to find meaning in supporting people with disabilities to build their lives.

Martha Perske
Since her first drawing appeared in the Greater Omaha Arc Gazette in 1971, the members of TASH and countless others have been impressed with Martha's stunningly powerful and sensitive drawings of people with disabilities as part of their communities. Martha is a self-taught illustrator with a marvelous gift for showing a person's disability and natural beauty at the same time.

Exemplary Achievement in Children's Programming:

Sesame Street
Since its inception over 33 years ago, *Sesame Street* has achieved well-deserved recognition as one of the preeminent children's education and entertainment programs in the world. Well before it became the politically correct thing to do, the originators of *Sesame Street* produced a program where the cast of characters - which includes Linda, the librarian who happens to be deaf - interact with and discuss people of different races, ethnicities, and abilities on a regular basis.

Exemplary Achievement in Disability Media Coverage and Advancement:

Janine Bertram Kemp
Jennifer Burnett
Steve Drake
Lucy Gwin
Tari Susan Hartman
Mary Johnson
Marcie Roth
Greg Smith
William Stothers
These individuals have been selected to receive this award in recognition of their career achievements and dedication to raising public, political, corporate, and mainstream media awareness in the area of media coverage for people with disabilities and their families. Through their efforts, the ability of these constituents to report on the issues affecting people with disabilities in a positive and empowering way has been raised to new heights.

Documentary:

Disability Culture Rap
Producers: Jerry Smith and Cheryl Marie Wade
Company: ACT
This high-energy delivery by Cheryl Wade shows disability culture as never before. Powerful images representing people of many different abilities provide a strikingly new perspective on disability.

Thinking Big
Producer: Eleanor Yu
Company: ABC News, "Hopkins 24/7"
Inspiring story about one of the most brilliant orthopedic surgeons in the world, Dr. Michael Ain, who specializes in treating dwarves, or little people. Dr. Ain is himself a little person, and has paved the way for other little people to pursue careers in the medical profession.

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TASH Recognizes Exemplary Achievement in Media with 2001 Images Awards

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Documentary (*cont.*):

Honorable Mention
Creative Expressions - Opportunities for Persons Who Are Deaf-Blind
Producers: DB-Link, The Blumberg Center and VSA Arts of Indiana
Honored for its positive emphasis on inclusion and its use of art as a means of communication.

New Media - Internet:

Laura Hershey <www.cripcommentary.org>
One of the pioneers of the online disability movement, Laura Hershey's writings, poetry and commentaries about disability have served to inform and impact a wide-reaching audience. Laura has demonstrated the power of the Internet to create a revolution.

Taylor Hines and Greg Schippel <www.stoppity.org>
Honored for the phenomenally well-organized, far-reaching, and effective media campaign designed to counteract the negative effects of the Muscular Dystrophy telethon and other vehicles like it that foster pity and disconnectedness among the broader community.

Business Week Online and John Williams "Assistive Technology"
Recognized for the partnership between Business Week Online and John Williams, and their successful collaboration in bringing issues that affect people with disabilities into the mainstream media.

New Media - Music Video

Honorable Mention
Secret Dreams
Producer: Fred Michael Beam
New, original, romantic, seductive and innovative music video with original music, song, performance, sign and dance all performed by deaf artists. The production is recognized for its diversity and its celebration of American Sign Language.

Print:

Washington City Paper, *"Before Their Time,"* (Oct. 27, 2001)
Author: Annys Shin
This compelling story depicts the struggle of young people with disabilities who have been forced to remain in nursing homes in Washington, D.C. The story is an accurate account, written in empowering language, and based on information obtained from people with disabilities as primary news sources.

Rosie Magazine, *"Mom Power"* (October 2001)
Rosie O'Donnell Interview with Laura San Giacomo
Honored for its refreshingly candid and straightforward interview by Rosie O'Donnell with "typical" mother, film and television star Laura San Giacomo, in which she talks about her son's cerebral palsy, and why she's fighting to make sure that all kids with disabilities get the same education as everyone else does.

Braveheart Press, *"Disability Is Natural"* and *"Presumed Competence"* Campaigns
Author: Kathie Snow
This successful print campaign has reached countless people worldwide. It has contributed to the shaping of positive images and the elimination of stereotypes.

San Francisco Bay Guardian, *"Pity This"* (August 29, 2001)
Author: Emily Teplin
Excellent analysis of why disability activists dislike pity approaches to what should be viewed as civil and human rights issues, and the harm that programs like the Muscular Dystrophy telethon cause by skewing public perception about the desires and abilities of people with disabilities.

Baltimore Sun, *"Race, disability: a double minority"* (July 24, 2001)
Author: Mike Adams
Recognized for its well-written discussion of various aspects of blindness, and its insightful discussion of a little touched on subject -- race and disability.

Wall Street Journal, *"Those Suffering Special Stress"* (October 18, 2001)
Author: Albert R. Hunt
A sobering look at how the horrific events of September 11 have impacted the security-consciousness of the nation. This story is honored for having raised awareness in the media that better emergency procedures must be designed for all people.

Public Service Announcements - Radio:

People with Disabilities/People First Language
Producer: Robert Futterman
Promotes the idea that people with disabilities are just like everyone else. Created as a series of generic announcements that can air on any radio station at any time of the year.

Public Service Announcements - Public Affairs:

Windows of Opportunity
Producer: Microsoft
Company: BLN-Seattle
Good company promotional video, depicting diversity and inclusion of people with a variety of disabilities throughout the company on an equal footing with employees without disabilities.

Public Service Announcements - Television:

WE Media's Disability Rights 2000 PSA Campaign
Producer: WE Media Inc.
Agency of Record: Trumpet Advertising
Extremely effective, well-done public service announcement about children and adults with developmental disabilities,

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Public Service Announcements - Television *(cont.)*:

portrayed with dignity and respect, and with a worldly and far-reaching vision of community and inclusion.

1) Learning 2) Working
Producer: Alberta Association for Community Living
Powerful public service announcement that promotes empowerment and values the civic participation of people with disabilities.

Television - Commercial Advertising:

Cingular Wireless
Cingular and the artistic abilities of Dan Keplinger received national acclaim for this commercial, which premiered during the 2001 Super Bowl, and emphasized the painter's incredible artistic talents and his means of self-expression through his work.

Television- Drama Series:

"Family Law"
Producer: Stephen Nathan
CBS Television
Honored for its ongoing commitment to accurately portraying images of people with disabilities as demonstrated by casting an individual with a disability, Allison Gray, in a recurring role, and its topical episodes which have served to create dialogue around disability related issues.

"CSI"
Producer: Jerry Bruckheimer
CBS Television
Recognized for its ongoing commitment to shaping positive images of people with disabilities as demonstrated by casting Robert David Hall in a recurring role.

Young People's Program -Animation:

Rocket Power, "Radical New Equipment"
Producer: David Rosenberg, Klasky Csupo Productions
Company: Nickelodeon
This episode of the popular animated series brings a character face-to-face with her own well-meaning but misinformed, misguided pity for another child -- one who happens to have a disability and one, she later discovers, who is as fierce a snowboard competitor as herself.

Clifford, the Big Red Dog, "A New Friend"
Producer: Deborah Forte, Scholastic Entertainment
Company: PBS
He's BIG, he's RED, and he's a great friend. He always stands up for what he thinks is right. Though Clifford's head is sometimes in the clouds (literally!), his four paws are planted firmly on the ground. Clifford's positive character traits are very much in evidence as he leads his canine friends to understand, accept, and embrace the new arrival in their neighborhood, a dog with three legs.

Pelswick
Producer: John Callahan and Nickelodeon
Company: Nickelodeon
The first animated children's program to feature a kid with a disability, Pelswick has captured the hearts of millions of viewers - both young and young at heart.

Honorable Mention
Futurama, "The Cyber House Rules"
Producer: Brian Cowan
Company: M. Groening
The grass is not always greener on the other side. So learns a character with a disability in this episode about accepting oneself for one's own special and unique gifts, and not attempting to get fixed or looking for a cure.

Young People's Program -Live Action

A Walk in Your Shoes
Producer: Danielle Bertarelli
Company: Nickelodeon
This unique venture between Nickelodeon and Sesame Workshop provides a much-needed educational media resource focusing on tolerance and diversity. This original series takes two real kids from different backgrounds and switches their lives while the cameras roll. The show is designed to help kids get a firsthand look at how people from different backgrounds and perspectives see the world.

My Louisiana Sky
Producer: Anthony Edwards
Company: Showtime
Recognized for its poignant and sensitive tale about a rural family's loving and positive support of one of its members with mental retardation during the 1950s, well before such terms and concepts were widely used.

TOKEN by Gail Bottoms

I've been called a lot of names,
Retard, Simple, downright Plain.
Now [a] new one I can claim
Add Token to my name

A Token they say sits on boards and committees and such,
You listen to plans but do not touch.

They have you there it is clear and plain
To be a symbol - consumer: guy or dame.
You're just a Token - they want your name.

We have a consumer on our board - we're good birds
But [you're] not given a chance to say a word.
If you say something, you're not heard.
You're just a Token - nothing more.

I guess of the names I can recall,
I hate Token most of all.

This poem was developed as part of the TASH Teleconference: Effective Strategies for Ensuring Self-Advocates are Involved in All Aspects of the Service/Support System on 9/25/01.

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Early Childhood Intervention Personnel Preparation: Backward Mapping for Future Planning

BY PAMELA J. WINTON

IMAGINE THIS: A group of toddlers and preschoolers are gathered around two adults during "story time." A teacher is reading from a big book with brightly colored pages that include English and Spanish words for different objects in the story. A graduate student from a nearby university is signing the story in American Sign Language (ASL) to a child in the group who is wearing a hearing aide. The children all have finger puppets that represent different characters in the story, and as a follow-up activity to the story the "puppets" take turns acting out roles in the story. One of the children uses a device that he operates with a switch to move his puppet when it is his turn. A child next to him helps upright his puppet when it falls off the device.

Off in the corner, a college student watches carefully and enters data into a portable laptop computer. She is evaluating an intervention designed to enhance friendships. She is part of an action research project designed by the teachers, university faculty, and students. The teachers have sought assistance from the university because they were worried about the social inclusion of a child with disabilities. One outcome of the collaboration has been that two of the teachers are receiving college credit for their participation in the research project.

The scene is being silently recorded on one of several videocameras that dot the ceiling of the classroom. Some of the footage will later be used for teaching a methods course at the community college. The cameras also record a small group of children who are husking corn with the help of a teacher's aide. Shelves holding pots and cooking utensils are labeled in English and Spanish.

A small beep causes the children to look up from their husking to a TV monitor in the room. "Hola," says the man on the screen who is sitting behind a steering wheel and wiping sweat from his brow, "Is lunch about ready?" The man is Juan, father of one of the children in the small group. Each day a parent is invited to join the children for lunch. It is Juan's turn today, and even though he cannot come in person, the classroom's electronic connections with home and family workplaces (including Juan's truck, which serves as his office) means that all parents can "visit" and contribute to classroom activities in numerous ways.

Juan is not only a frequent classroom visitor, he is also a member of the "Accountability Council," a staff-parent group engaged in a self-study of the program. He has committed 10 hours a month for 18 months to this project. The financial reimbursement that Juan receives makes it possible for him to take time away from his landscaping business.

Personnel preparation is an ongoing part of the fabric of daily work. The driving force behind the content and specific educational activities is the basic question, "What do we need to know and do to improve the outcomes for all young children?"

In another area of the classroom, a community college student is facilitating block play among a group of children.

The scene is being observed by the master teacher in the program, who is also a part-time instructor in the community college program. Although she has just finished her doctorate in early childhood, she will remain with the program. The chance to supervise students, teach at the college level, and still have some time with young children makes her job particularly fulfilling. While children are napping, teachers and aides are busy with other credit-earning activities that are part of each staff person's individualized professional development plan. Members of a small peer coaching team discuss their notes from classroom observations. A teacher and aide work together on a web-based computerized instructional module on early literacy. An early childhood intervention consultant visits 4 times a week to provide follow up to the web-based instruction and to demonstrate and provide feedback as teachers and aides implement strategies.

Parents have found the web-based instruction and video footage particularly helpful in strengthening the home-school partnership. Home visits by the consultants supplement what parents learn through technology, and parents and teachers say the opportunity for parents to observe teachers using particular techniques in the classroom encourages the exchange of ideas with each other on a regular basis. Some of the parents have opted to get college credit for their involvement in web-based instruction. The consultants are members of one of several transdisciplinary teams that make up the local unified early childhood intervention system in the county. Children with disabilities are served by the same team until they reach age 8.

Community-based teams (also known as "learning pods") consisting of the preschool staff from 3 centers, public

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school kindergarten teachers from the neighborhood elementary school, an early intervention team, parents, and faculty and traditional students from both 2-year and 4-year colleges, participate in quarterly workshops as part of a community-wide professional development plan. The county has several "learning pods," each unique to specific parts of the community. Cross-site visits and community-based peer coaching groups have been especially helpful in promoting positive changes in classroom practices, according to evaluation data being collected through the grant.

A critical part of the success of the county's professional development activities is a cadre of committed and trained substitute teachers and volunteers who help on a daily basis in the early childhood programs. Many of the substitutes are retired teachers. In addition, program administrators receive support for orchestrating the program's specific and community-based staff development activities. This is a large part of their job, and they work closely with the master teachers who are responsible for overall evaluation of their programs' staff development plan. The business community has provided the technology expertise and support critical to the strong communication links that are part of the system.

Because the various training activities are linked with increases in compensation for staff, turnover has decreased by 75% over the last decade. The positive impact on children has been documented. Goal 1 of the Year 2000 educational goals for the county was finally met in 2020. Children are now entering school ready to learn according to teacher and parent perceptions, observations, and standardized outcome measures. Of course, school entry has a completely different meaning now. Public schools are part of the unified early childhood intervention system. Universal pre-kindergarten for some toddlers, and all 3- and 4-year-olds has been mandated for years now. Because of liberal and flexible family leave and family support policies, the number of infants in group care has greatly diminished over the last decade.

At a retirement party for the administrator of the program, the students in their 20s are shocked when they hear stories about the working conditions, low salaries, and education levels of early childhood staff "back in the day." The "Children's Revolution" that brought about the massive policy changes in the early 2000s accomplished more than these young students imagined. Would they have pursued careers in early childhood under the old conditions? Probably not was what they said.... It was not simply the salary and status differentials of the old days. They simply could not imagine the isolation and fragmentation of a system that did not include time for planning, reflecting, and making improvements. In 2030 with federal, state, and local budgets and policies realigned to reflect the public priority for early education and family support, they feel like valued members of the workforce. What a difference a generation can make.

❖ ❖ ❖ ❖

Embedded in this vignette is my vision for personnel preparation in the future. The centerpiece of the vision is a well-paid, well-educated early childhood intervention workforce situated in "learning communities" whereby parents, practitioners, administrators, consultants, and university and community college faculty are mutually accountable for creating quality early environments for all children. Personnel preparation is an ongoing part of the fabric of daily work. The driving force behind the content and specific educational activities is the basic question, "What do we need to know and do to improve the outcomes for all young children?"

The specific features of this vision for personnel preparation include the following:

- Personnel preparation is guided at the community, program, and individual levels by integrated, collaboratively developed personnel development plans. Responsibility for planning, implementing, and evaluating the plans is shared among disciplines, agencies, institutions, and individuals.
- A variety of models and strategies for personnel preparation are available and accessible for meeting the needs of learners, including individually guided instruction, observation/ assessment, action research, peer coaching, direct teaching, modeling and demonstration, lectures, readings, and workshops. Professional development activities take place predominately in early childhood environments.
- Emphasis is placed on learning in teams and through relationships.
- There are structures (career ladder) and concrete incentives (credit toward college degrees, promotions, pay raises) that support staff for engaging in professional development.
- The impact of personnel preparation on the implementation of new practices and child outcomes is evaluated at the individual, program, and community levels.
- Families have options for active and meaningful involvement in all aspects of personnel preparation, including monitoring and evaluating outcomes.

Some features of the vignette are not visionary at all. Personnel preparation programs with some of these features

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can be found in many communities. Existing guidelines for professional development include many of the features highlighted above (Collins, 1999; Winton, 1994; Winton, McCollum, &; Catlett, 1997).

However, some of the features, especially those dealing with policies and resources, seem unobtainable. A vision for the future should have some chance for realization. Which elements of this vignette are possible? Can certain features be achieved without others? Is a "Children's Revolution" a necessary prerequisite for securing the resources that would support this mythical early childhood program and personnel preparation system of the future?

This article focuses on three areas where change is well within our reach: interagency, interinstitutional, and interdisciplinary collaboration; appreciation for diversity; and family involvement. These areas are not new ones. In fact these are some of the "catchwords" of the 1990s. The challenge is how to move from talk to action. By starting with this vision, and mapping back to the present, I hope to identify stepping-stones for realizing what is now fantasy.

INTERAGENCY, INTERINSTITUTIONAL, AND INTERDISCIPLINARY COLLABORATION

The vignette paints a picture of collaboration in personnel preparation occurring across multiple partners, disciplines, institutions, and levels. Two events highlight the extent of our collaboration challenges and how slow progress has been over the last decade. The first event was a 2000 statewide meeting on personnel development. During the meeting a faculty member stated, "What I need and can't find are quality early childhood practica sites where inclusion is being practiced." Later in the meeting a program administrator said, "What I need and can't find are therapists who can work in consultative roles in childcare settings." It is no wonder we are not achieving our goals for inclusion; recent research suggests that families of children with disabilities are facing the same challenges they faced 20 years ago when seeking inclusive early childhood programs (Erwin, Soodak, Winton, & Turnbull, in press).

To achieve the kinds of university-community partnerships portrayed in the vignette, we must eliminate the traditional boundaries between preservice and inservice.

Examples of effective inclusion are hard to find, so students are not able to see demonstrations of effective inclusion practices. Therefore, they enter the workforce unprepared to implement inclusion, which perpetuates the lack of acceptable practica sites. This "catch-22" situation persists, in part, because neither faculty nor program administrators see the problem from a perspective that suggests they have some responsibility for the solution.

We must break these kinds of cycles and strengthen collaboration among institutions of higher education and community programs and practitioners. It is not that we lack knowledge about effective classroom practices that promote inclusion. Research has defined quality early childhood environments (CQO, 1995) and identified critical components to implementing inclusion in early childhood settings (Odom, 1998). Faculty and practitioners have a mutual responsibility for using this information to make changes in program practices. To achieve the kinds of university-community partnerships portrayed in the vignette, we must eliminate the traditional boundaries between preservice and inservice.

The second event that stressed our collaboration challenges was an interdisciplinary panel of early childhood interventionists that I convened for an interdisciplinary graduate class on working with families and teams. The panelists were all excellent role models, espousing family-centered, collaborative beliefs and practices in their responses to a case vignette. The students were impressed with their expertise and sensitivity in dealing with the complex issues raised.

However, students were shocked when it became apparent that most of the panelists, some of whom shared children on their caseloads, had not personally met each other prior to the panel, even though they were working in the same community. Students also realized that families needing their services would have to travel to different sites, negotiate different forms and reimbursement procedures, and so on, to benefit from the professionals' expertise. Most appalling was the realization that there was no guarantee that the collective power of this particular group would ever be focused on a real child. It took a class simulation to create this particular "team." The lessons on the importance and challenges of interagency coordination were beautifully (and tragically) illustrated by the panel.

For a decade, we have operated on the belief that a small amount of federal support for state and local level interagency coordinating councils, along with some talk about the importance of interagency collaboration, would be enough to transform the myriad of agencies and institutions providing services to young children with disabilities into a "seamless early intervention service system" (Shonkoff & Meisels, 1990). We hoped to conquer the chasm that exists in most states between the Part C services for infant to 3-year-olds and the Part B services for 3- to 5-year-olds by requiring that transition plans be part of the early intervention services provided to families. We also hoped that statewide personnel development committees

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with meager budgets, dependent on volunteers working across geographical distances, would solve the challenges of state and local agencies having different training initiatives, budgets, and priorities. Granted, some progress has been made; however, new collaboration challenges have emerged.

In the original early intervention legislation, early education was not one of the key disciplines. With the legislative priority for services to be provided in natural environments (IDEA, 1997), early education has become one of our most important partners. As we have embraced this new partner, we are discovering that early education is in and of itself a fragmented "non-system" in terms of funding, philosophy, and professional development.

I have been convening interdisciplinary panels since 1988. Now former students who leave our graduate program as "change agents" are the professionals who are part of the panel and part of the system; yet some of the challenges of 1987 are the same as those in 2000. For every collaboration challenge solved, two more emerge. If our well-educated, motivated graduates cannot change the system, it makes me wonder who can.

Promising Initiatives

Initiatives that promote effective and collaborative personnel development efforts can be found at the national, state, and local levels. Both "top down" and "bottom up" efforts are absolutely necessary and must be encouraged if there is any hope of making progress in creating the kind of "learning communities" (Fullan, 1993) described in the vignette. What follows are some examples of promising initiatives that strengthen collaboration, especially between institutions of higher education and communities:

- The Hilton/Early Head Start Project exemplifies a blending of foundation and Head Start support for collaborative training. Community-based teams, including Early Head Start and early intervention staff, and parents whose children with disabilities are being served, participate in ongoing professional development activities related to inclusion and disabilities. Preliminary evaluation reports suggest the project is successful in enhancing inclusion and building teamwork (Hilton/Early Head Start Quarterly Report, 1999).

- Federal grants (U.S. Department of Education, 1998) have funded a number of university-based personnel preparation grants that prioritize community-higher education partnerships. Some exemplary models for embedding university training in community-based settings have been developed and supported through these grants (e.g., McCollum & Yates, 1994).

However, research by Rooney (1995) indicates that many interdisciplinary personnel preparation programs funded through the Office of Special Education Programs (OSEP) grants revert to their unidisciplinary focus once the funding ends; these data do not inspire confidence in this approach as a single solution. Grant reviewers could pay more attention to ways universities will institutionalize these projects when deciding which projects to fund.

- A small number of states (e.g., Nebraska, Oklahoma, and North Carolina) have created Requests for Proposals (RFPs) for funding innovative community-based, family-centered, interdisciplinary preservice programs, as a way of instigating changes and collaboration among families, communities, and universities and community colleges. These efforts have emerged as part of these states' participation in federally funded faculty training projects based on a systems change model (see <www.fpg.unc.edu/~scpp> for more information). If these efforts are evaluated and proven to be successful, they may become models for other states to follow.

One of the goals of the series of federal grants that focused on systems change in personnel preparation is to assist major stakeholders (those with the knowledge, power, money, and authority to conduct early intervention training) at the state level to identify all of the different early intervention training initiatives in their state and then consider ways these efforts can be integrated more effectively (Winton, 1996).

It is always an interesting task, and in many states has led to state-level collaboration between groups that essentially were engaged in "parallel play." The same task could be accomplished at the community level and could perhaps lead to the concept of a "community-wide personnel development plan," which was mentioned in the vignette. Perhaps Local Interagency Coordinating Councils (LICCs) could take this initiative. In fact, they may already be taking this role in some communities; if so, they will want to share information about it. Collaboration around early childhood intervention personnel development at the community level is a promising but somewhat unexplored direction (Wesley & Buysse, 1997).

> *We know what constitutes an effective personnel preparation system, just like we know what makes an effective early childhood intervention program. The question is whether that information can be shared in ways that make the need for changes in policies and practices undeniable. It will take a nation of informed "learning communities" to make this vision a reality.*

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APPRECIATION FOR DIVERSITY

The vignette suggests that teachers are comfortable and competent working with bilingual children and in a multicultural environment. Current research indicates that this represents a substantial change from our current situation; a national survey indicated that less than 20% of our nation's teachers who work with culturally diverse students feel well-prepared to meet the needs of these students (U.S. Department of Education, 1999).

By 2030, the non-Hispanic White population will be in the minority of the U.S. population under 18 (U.S. Department of Education, 1999). Unless we are able to create a major change in current trends, the majority of teachers, administrators, and consultants serving young children and their families will be White (AOTA, 1990; ASHA, 1995; DEC, 1997). We have two pressing goals: to address the absence of diversity in our early intervention teacher and leadership corps and to promote the competence of personnel working with ethnically and linguistically diverse students and families.

Research conducted by the National Black Child Development Institute (Moore, 1993) suggests that one of the significant contributors to the absence of diversity in early childhood leadership are the barriers created by higher education. Degrees and credentials convey authority, credibility, and pave the path to leadership positions. Therefore, it is particularly important that we examine factors that can be changed in institutions of higher education. Hurtado, Milem, Clayton-Pedersen and Allen (1999) identified four levels of change that must be addressed simultaneously: structural characteristics of training programs (e.g., number of minority students enrolled, number of minority faculty, number of courses focused on diversity); historical legacy (e.g., mission, history of racism and exclusion); psychological climate (e.g., attitudes and perceptions of discrimination and prejudice); and behavioral factors (e.g., knowledge and skills of students and faculty, pedagogical practices used in the classroom that reflect sensitivity to differences).

A recent review of the literature on early intervention personnel development related to diversity issues indicated that we have much work to do in all of these areas (Hains, Lynch, 86 Winton, 1999). It suggested that we need to look to other disciplines, such as counseling (Pontoretto, 1996) and early childhood (Alvarado et al., 1999; Derman-Sparks & Phillips, 1997), that have a longer history in addressing diversity for help in moving forward as a field.

In talking with other early interventionists who share an interest in diversity issues, I am struck by several things. There are perceived risks in getting involved in the topic; these risks include being misunderstood, using the "wrong language," becoming involved in controversy and misunderstanding, and becoming exhausted from being a "lone voice." Whites who are interested in promoting discussion of the topic sometimes fear they lack credibility. Persons of color interested in the topic sometimes feel the people with the power to make changes are not interested in participating in dialogue; those who are interested represent a small handful of people, and they are tired of "preaching to the choir." Clearly, partnerships are needed if we are to make progress in this personnel preparation area of critical importance.

Promising Initiatives

Some of the promising early childhood intervention initiatives that address increases in diversity at leadership levels and promote competence in working with diverse children and families include the following:

- The National Black Child Development Institute has initiated an Early Childhood Leadership Corps to promote diversity in early childhood leadership through student fellowships (National Black Child Development, 1999).
- The U.S. Department of Education (OSEP) has funded minority personnel preparation grants and a special institute (Culturally and Linguistically Appropriate Services Early Childhood Research Institute) to increase leadership and promote competence around diversity issues (1998).
- Wheelock College has foundation support for their Taking the Lead Initiative (Alvarado, 1997), designed to increase early childhood leadership opportunities with certain projects focusing on diversity.

FAMILY INVOLVEMENT IN PROFESSIONAL DEVELOPMENT

The vignette shows families being involved in their children's early childhood program in a variety of ways, several of which relate to personnel preparation. Families in the vignette had many of the same personnel preparation options that teachers had, and they were supported in their involvement through incentives, such as reimbursement and course credit. They were viewed as team members and "equals" in these activities. Information and expertise were shared through a two-way process. Parents were also shown taking a leadership role in terms of program self-assessment and evaluation.

In a 1999 issue of Topics in Early Childhood Special Education (19:3, a set of articles on parent education suggested that we do not have uniform agreement about how parents should be involved in personnel preparation. A central theme to the articles in TECSE was agreement that options and choices for families are centrally important.

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One strategy for solving definitional issues is to encourage each early childhood program to develop its own unique definition of family involvement within some broad parameters, and to include family members in the development of that definition. In other words, by including families in active, meaningful decision-making roles about program policies and practices, programs will construct meaningful family involvement strategies (Winton & Crais, 1996). The family involvement strategies will evolve in response to community and policy changes and the evolving needs of families in the program.

The "Accountability Council" mentioned in the vignette is the kind of structure that I can envision for making that possible. One advantage to this kind of approach is that it provides a different kind of structure for parent advocacy. Historically, we have depended on parents to do the bulk of our advocacy work. The reasons often cited include the following: Parents have more credibility; when professionals advocate for more or better services, it seems like we are trying to protect our jobs; and parents are successful; their stories make an emotional and immediate impact on policymakers.

However, there are some disadvantages for parents. They become tired of the role over time and do not feel supported or appreciated by the systems they are trying to change; this can create stress, tension, and fear that their children will suffer as a result of their advocacy (Erwin et al., in press). We need to find creative ways to incorporate parent knowledge of program strengths and weaknesses and their desires for making improvements into our ongoing program evaluation efforts.

Promising Initiatives

There are some promising initiatives that provide stepping-stones to achieving this vision for family involvement in personnel preparation:

- Parent Training and Information Centers, Family Support Networks, and other family advocacy organizations that provide support to families in leadership roles are in place in all states and in many communities (Council for Exceptional Children, 1999).

- Federal grants (U.S. Department of Education, 1998) support a number of innovative training programs and initiatives that provide models for including families in leadership roles.

- A few states, such as Kansas and Alaska, are including parents as part of early intervention program monitoring and evaluation teams (Winton & Crais, 1996).

I began the article with the suggestion that a revolution might be necessary to bring about the changes in policies and resource allocation needed to support my vision of personnel preparation. However, I also suggested that taking small steps in the areas of collaboration, diversity, and family involvement could bring slow but steady progress toward the vision and in fact might help with the revolution. How? It will take a "learning community" of families, practitioners, administrators, faculty, researchers, and businesses to develop the shared vision and commitment to change our national priorities around early childhood.

Without that shared vision and commitment at the community level, we will continue to operate with a massive gap between what we know from research and how we practice. We know what constitutes an effective personnel preparation system, just like we know what makes an effective early childhood intervention program. The question is whether that information can be shared in ways that make the need for changes in policies and practices undeniable. It will take a nation of informed "learning communities" to make this vision a reality.

From "Early childhood intervention personnel preparation: Backward mapping for future planning," by Pamela J. Winton, Summer 2000, Topics in Early Childhood Special Education, 20, 87-94. Copyright 2000 by PRO-ED, Inc. Reprinted with permission.

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TASH Adopts Death Penalty Resolution

TASH has adopted one of the nation's most powerfully worded resolutions opposing the execution of persons labeled as having mental retardation. The adoption of this resolution comes at a critical time in the determination of federal legislation on this crucial issue. The U.S. Supreme Court agreed in September that it will hear the appeal of Daryl R. Atkins, a man who is labeled as having mental retardation and who has been convicted of murder in Virginia.

Many people consider this case to be one of the most significant the Supreme Court will hear this session. A decision will be based on whether a majority of the justices finds that there is a national consensus against executing people with mental retardation. This issue was last considered by the Court in 1989 and the practice was upheld. Justice Sandra Day O'Connor's 1989 opinion said the best evidence of a national consensus that the punishment was "cruel and unusual" would come from the laws passed by state legislatures on this issue.

TASH's adoption of this resolution was initiated by long time TASH member, Bob Perske, who drafted the resolution's original language.

❖ ❖ ❖ ❖

TASH Resolution Opposing the Execution of Persons Labeled as Having Mental Retardation

Statement of Purpose

TASH unconditionally opposes the execution of persons labeled as having mental retardation[1]. Although TASH promotes the full participation of all persons with disabilities in society, one of its many missions pinpoints the United States Supreme Court's current effort to decide whether it is constitutionally right or wrong to execute persons considered and/or classified as having mental retardation. TASH believes that executing these persons is so repugnant that, in every case, it violates current American standards of decency.

Rationale

1. Thirty states currently prohibit the execution of persons labeled as having mental retardation. TASH is committed to assisting the remaining twenty states to develop legislation that will prohibit the execution of persons with these disabilities.

2. TASH recognizes that any persons, including those labeled as having mental retardation can commit capital crimes. TASH calls for a more humane and just determination of what the sentence should be for individuals with disabilities.

3. Societal discrimination, lack of education, as well as an individual's personal abilities affect how persons labeled as having mental retardation perform within society. Given the nature of discrimination against people with disabilities, as well as the real challenges that these individuals may experience in communicating and processing information, it is to be expected that when accused of a crime, such persons may inappropriately blame themselves, assume responsibility for the criminal conduct of others, fail to remain silent in their own defense, provide false confessions, or give criminal justice authorities the responses they seek without regard for the truthfulness of such responses.

4. An accused person's communication and thinking abilities are significant at every stage of a capital case, including initial police questioning, determining competency to stand trial, the guilt/innocence phase of the trial, the sentencing phase, and all subsequent proceedings, including consideration of clemency. The behavior and responses of a person labeled as having mental retardation may appear unusual or different and may result in misunderstanding, trigger special scrutiny from police officers, or result in unfair proceedings at any stage of the criminal justice process.

5. In these cases, Miranda warnings are often meaningless because they are presented without appropriate accommodations to a person's disability or vulnerable circumstance. Some individuals labeled as having mental retardation are so adept at combating and avoiding stigmatization they fail to be candid about their disabilities when to do so could be in their best interest. For these reasons, it is likely that persons with these disabilities may be unable to respond voluntarily and effectively in their own defense.

6. Defense lawyers may fail to recognize the vulnerability of their clients, may be ignorant or unskilled in how to support these persons in the criminal justice process, or may fail to recognize an accused individual's difficulty or inability to assist in his own defense in court proceedings.

7. A prosecutor may call for the death penalty or a judge and jury may impose the death sentence without considering the status of disability as a significant mitigating factor and without understanding the impact of societal discrimination or the vulnerability inherent in having a disability such as those described.

8. Taking all of these factors into account, persons labeled as having mental retardation do not have the opportunity for a rational, individualized, fair determination of sentencing.

THEREFORE BE IT RESOLVED, THAT TASH, an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field, believes that it is beyond the ability of the criminal justice system adequately to assure the fairness of death sentences in these cases and that such sentences are, in all cases, a clear abridgement of the rights of persons considered and/or classified as having mental retardation.

•••

Sources that influenced this document:

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Earnest Paul McCarver v. State of North Carolina. The Amicus Curiae Brief of The American Association on Mental Retardation, The Arc of the United States, et al. http://www.aamr.org.

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[1] When the term "labeled as having mental retardation" is used within this resolution, it is meant to include all individuals who would fall within the legal definition under Section 504.

A Guide to Achieving Successful Inclusive Child Care -- The Harry Potter Way

BY PEGGY FLORIO

With the popularity of the books and the subsequent release of the movie, Harry Potter has become a household name, particularly for families of young children. The world of wizardry, although fantastical in our thinking can have many lessons and analogies to finding inclusive child care. With the right combination of ingredients, something magical can be created.

Thinking about the story of Harry, a child with unique talents and special needs, posed challenges when finding the appropriate environment. Harry's placement with his aunt and uncle, the Dursleys, was less than ideal. While there, Harry's room under the stairs certainly did not meet licensing requirements for adequate square footage per child; his aunt and uncle were less than nurturing; and Harry's developmental needs as a young wizard were ignored. Harry did not have a choice in that placement, but when you do choose, it is important to check out every aspect of the environment carefully.

Sometimes locating child care that meets your family's needs may feel like you're trying to gain access to Platform 9 3/4 , i.e. through a brick wall! For Harry and all of the young wizards striving to reach school via the Hogwarts Express, access could only be gained by walking quickly and purposefully through the barrier wall between train platforms 9 and 10. The maneuver required trust and an unwavering positive belief that you would succeed.

Without those key strategies, passed onto him from the parents of other young wizards, Harry would have surely slammed into the wall, his greatest fear. The Dursleys' laughed at Harry for even daring to believe that a place like Platform 9 3/4 existed. Like Harry, parents of young children with disabilities learn from each other, and require persistence, trust, and positive desire to succeed.

As demonstrated above, one can achieve what seems impossible even without a magic wand! With the right tricks of the trade, the process for families of children with special needs can go smoothly. First, when looking for a program, have in mind what your needs are logistically. There is not much reason to invest a lot of time exploring a program that doesn't open early enough or is cost prohibitive. One of the first questions you ask should be, "Do you have openings for a ___ year old?" This not only is a time saver, but also when looking for care for a child with disabilities, this helps you to define whether a program is truly open to caring for children of all abilities.

Many parents have stated that when they begin the conversation with caregivers describing their child's needs they suddenly are told about waiting lists and lack of openings for the age group they require. They cannot tell if the lists really exist for all children. Ask about openings first. Once you determine there is an opening, it is important for child care providers to first get to know you and your child. Remember, your child is a lot more like typically developing children than he or she is different. Model this belief for the caregivers. It is recommended that you have your questions ready, and only mention your child's disability after you think this is a program you might be interested in using for care. There is no sense in putting yourself through disappointment and discouragement of situations not working out because someone isn't willing to care for your child, when in reality even if they had been willing and open to the idea, you weren't satisfied with the program.

The next step in securing a successful child care situation is to visit various programs that seem to be appropriate for your child and family needs. Visiting programs can draw parallels to Harry's first trip to Diagon Alley -- the underworld of wizards. You may see things that excite you, you may see things that make you nervous, or you may see things you simply don't understand. It may be like entering a whole new world. Some questions you may find helpful to think about when visiting sites include:

❖ Does the program look clean, safe and accessible?

❖ Is the ratio of adults to children adequate?

❖ Do toys and materials support different types of learning?

Preparing the childcare provider will likely require specific training and preparation. Your child may need picture schedules, behavior plans, or adaptive equipment. Remember, what seems natural or ordinary to a family member, may once have seemed unusual or even scary. It is important to understand the provider's level of understanding and comfort. Meet child care providers where they are, and help them to feel comfortable.

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A Guide to Achieving Successful Inclusive Child Care --- The Harry Potter Way

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- Does the environment show respect for different cultures, languages, values, and traditions?
- Are staff actively involved in every aspect of the child's day?
- Do the staff seem flexible about adapting activities, environments and curriculum?
- Are you comfortable with the way staff discipline the children?
- Do caregivers seem to enjoy and respect the children?
- Are the children given the chance to make choices?
- Are the children engaged in activities that suit their age and stage of development?
- Do the children appear to be happy and enjoying themselves?

Once you've narrowed your search down to two or three settings, it's time to make a choice. When a young wizard arrived at Hogwarts, a magical hat was placed on his head. This magical hat helped determine in which dormitory each wizard would reside (it was the Gryffindor for Harry). You are the keeper of the sorting hat for your child. You know the information you need, you must carefully weigh your options and then trust your "gut feelings" or "parental intuition" to serve you well in making the final decision.

Locating child care is only one ingredient in brewing a successful situation. Once a program has been chosen, there are some critical elements to ensuring success. First and foremost, preparation is crucial. Think about Harry's Quidditch team — not only did they need to secure the proper equipment, but they required training. Quidditch, a game with flying brooms, is not well known to the average person.

Preparing the childcare provider will likely require specific training and preparation. While they won't need a golden snitch or a nimbus 2000 broom (the top of the line flying broom), they may need picture schedules, or behavior plans, special scissors or a special chair. Remember, what seems natural or ordinary to a family member, may once have seemed unusual or even scary. It is important to understand the provider's level of understanding and comfort. Meet child care providers where they are, and help them to feel comfortable.

One of the best ways to do this is to provide them with information. Think about all aspects of your child's day, what comforts him or her, what to do in emergencies, your child's favorite and least favorite things. If available, share assessment information, allow child care providers to visit your home or another place your child may work or play throughout his or her day.

Find out how your new caregivers learn best. Do they do better with written materials, demonstration, being told? Allow time for practice, time to transition and become comfortable, not only for your child and caregiver, but for yourself as a parent as well. If there are resources that can offer additional supports such as Project ACT (All Children Together) in Maryland, utilize them to help facilitate a successful situation.

Effective communication between home and school at Hogwarts happened via owls, and though that is not practical in our world, there are some important lessons to learn from how communication occurred in the wizarding world. The owls came at regular intervals, daily in fact, to present information. They came with gifts and warnings. They carried critical information from one world to the other. Every wizard understood and valued their contribution and role.

Communication between home and child care needs to be clear, understandable and occur regularly. Try to always have something positive to say and avoid jargon. Although you don't want do deny concerns, present them in a strength-based manner, and try to avoid "howlers" or screeching at all costs!

When all the ingredients are well mixed, your child will be comfortable, and most likely will build lifelong friendships much like Harry, Ron, and Hermoine. Just remember as is often true at Hogwarts — the unexpected can and will happen. Like the stairs in the castle which suddenly change directions on the wizards, requiring them to think quickly and devise an alternate route, you may find various changes from time to time in your child care placement. Your child's needs will also change over time, which makes communication, ongoing training and the spirit of teamwork essential. In the case of difficulties, you or someone on the team will need to be like Hermoine. In the climax of the story when the devil's snare was strangling Ron, Hermoine was able to relax — take a deep breath and remember all she had learned. You can too.

Peggy Florio is Director of Project ACT in Towson, Maryland. For additional resources on locating inclusive childcare, contact Project ACT, 300 E. Joppa Road, Suite 1103, Towson, MD 21286; Phone: (410) 828-7700; Fax: (410) 828-7708, or visit ACT's website at www.abilitiesnetwork.org

Early Childhood Intervention Personnel Preparation: Backward Mapping for Future Planning

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The Story Behind the Name Change That Never Happened

Continued from page 5

When we discover that the young adult with autism is in fact, at least as bright, maybe even more so than his teacher, does he no longer qualify as having a severe disability? The perception of intellectual or cognitive ability has been closely tied with a person's ability to communicate in conventional ways. When a person who is perceived as having severe cognitive disabilities is finally given the sophisticated communication device to which she is entitled and begins to advocate for herself, does she no longer have a severe disability? When people who have "graduated" from being advocated for, because the perception by some has been that they have a severe disability, to being self-advocates (another label by the way!), does TASH no longer advocate for their continued self-determination? Can, in fact, a person who has a severe disability one day not have a severe disability the next, or can a person have a severe disability in one environment and not in another because he/she has been characterized based solely on perception?

The terminology of "severe disabilities" tends to be professionally oriented. It has been and currently is used to describe a field of study in teacher education as well as other training and technical assistance initiatives. This generates another concern that if we do not reflect "severe disabilities" in the name, it will make it difficult for university faculty and students as well as educators and service providers to access TASH and JASH through an online search as an example. The committee discussed whether parents of a child with a severe disability would fail to stumble across our web site -- or do parents really think of their sons and daughters as having what some professionals would call a "severe disability?"

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The Story Behind the Name Change That Never Happened

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Finally, does the term "severe disability" mean anything to the lay public who might see it in the title of an organization? My personal experience is that people often have to ask, "Who are you talking about?" Having to ask or answer this kind of question ultimately defeats one purpose of having the descriptive term in the title and again, what we find is that there is no clear answer to who fits the definition and who doesn't. These issues represent only part of the debate about terminology and certainly I have only provided a simplistic view of the broader issue.

There was however, a discussion that began at the conference by one of our recognized leaders in the field of "severe disabilities" about disability terminology needing to reflect the conditions of inaccessible and unaccommodating social and physical environments as opposed to reflecting the person as having an inherent "problem." The next few years will be interesting!

The Mission

I don't mean to give the impression that the name change process was pure controversy. The phone meetings, face-to-face dialogs, and e-mail discussions around TASH's mission and purpose were the most revealing about where the diversity of thought ends and where the unity of this organization begins. Although we struggled somewhat with how to word the mission statement, the focus was clear and supported by all with whom I spoke regardless of what their position on what the name of the organization should be. All participants agreed that we are in the business of ensuring that when we say, "All means all," that the focus is on those individuals who are continuously excluded from the "all." Our mission is focused on abolishing the factors that prevent those individuals who have traditionally been labeled as having severe disabilities from having the opportunities that are afforded to the other 95+% of the "all." Hopefully by describing the conditions under which people with disabilities are educated, are working, and are living, we have begun to change the descriptive language from focusing on the person as the source of the disability to focusing on the environment as being the disabling or limiting condition.

Another issue that was raised from time to time during this process was about the necessity of having a focus on research in this organization's mission. In the end, name change committee members unilaterally agreed that without solid research into the efficacy of good practice we have no tools to give to the attorneys who are fighting every day in the courts for the rights of people with disabilities to inclusive education, supported work, and life in the community.

Without the research we would have no ammunition to give to parents of young children about to enter the system of segregation. Without the research that the university faculty, students, and other professionals conduct with and without government support, there would be no standard of what constitutes best practice and no proof that any of what we advocate for can be realized. Without the research into communication, we would not know how best to promote self-determination. And without research, we could never get past the door with our legislators who demand proof of everything. Trying to convince people to do something because it is the right thing to do is not enough -- we have to prove that our progressive ideas work and result in better lives for people with disabilities and their families.

And in the End

Now that the name is back to being just "TASH," I find it ironic how well the name might fit at this time in the life of our organization. There is no language in the title -- no "severe," no "disability," no "social justice" or "human rights" or "research" -- no "adults" or children." In short, nothing that can be misconstrued although certainly nothing that conveys our mission. The promotion of TASH is totally dependent on the mission and how we as members convey that mission. I am confident that we are all on the same page in this regard.

I know that I have not done justice to all of the issues behind the name change because of their complexity, but hopefully I have answered questions about how we got to this point. In closing, it is not about what TASH does for you the professional, for you the self-advocate, for you the parent. It is about what each of you brings to the organization that will ensure that TASH fulfills its mission. When you read the new mission statement, please think of the contributions you bring to the organization and about the daily impact you have now and can have in the future toward making the mission of TASH a reality.

We're looking
for you!

Attention TASH Members!

The Paraeducator Interest Group is seeking contact information from members who are interested in issues related to the employment, deployment, training and support needs of paraeducators.

If you are interested in issues related to paraeducators, please send an e-mail to Nancy Weiss at the TASH central office <nweiss@tash.org> expressing your desire to be a member of the Paraeducator Interest Group. We will send respondents a copy of the TASH Resolution on Paraeducators, build a resource network and communicate relevant information to you.

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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